State Snapshot 2021-2022:

Early Psychosis Programming Across the United States

EPINET
Early Psychosis Intervention Network

Preparation Notice

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List of Commonly Used Acronyms

ACE	Adverse Childhood Experience
BARS	Behaviorally Anchored Rating Scale
BPRS	Brief Psychiatric Rating Scale
CAB	Core Assessment Battery
CBT	Cognitive Behavioral Therapy
CHR	Clinical High Risk (for Psychosis)
CMHC	Community Mental Health Center
CSC	Coordinated Specialty Care
CSI	Colorado Symptom Index
DUP	Duration of Untreated Psychosis
EASA	Early Assessment and Support Alliance
EPINET	Early Psychosis Intervention Network
ESMI	Early Serious Mental Illness
FEP	First Episode Psychosis
MHBG	Community Mental Health Block Grant
PCL-5	PTSD Checklist for DSM-5
QPR	Questionnaire about the Process of Recovery
SAMHSA	Substance Abuse Mental Health Services Administration
SMHA	State Mental Health Authority

Introduction

This State Snapshot provides information regarding early psychosis programming across the United States. Early psychosis programs emerged as a federal priority based on growing scientific evidence accumulated from other countries, such as Australia, Canada and the United Kingdom, as well as from the NIMH funded Recovery After an Initial Schizophrenia Episode (RAISE) initiative. Additionally, Congressional concern about psychotic disorders among adolescents led to legislation expanding the Mental Health Block Grant (MHBG) set-aside funds for evidence-based programs addressing first episode psychosis.

All U.S. states and territories receive federal MHBG funds each year, which are administered by the Substance Use and Mental Health Services Administration (SAMHSA). In 2014 and 2015, Congress directed SAMHSA to establish a set-aside for evidence-based programs for individuals with serious mental illness and psychotic disorders, correspondingly increasing MHBG funding for this set-aside. Each state and territory was directed to spend at least 5% of their MHBG funds to address the needs of this population. SAMHSA and NIMH later specified that this set-aside should focus on the treatment of early psychosis, encouraging states to develop Coordinated Specialty Care (CSC) programs. CSC is a team-based program that includes a set of evidence-based outpatient services, including the following components: case management, psychotherapy, supported employment, supported education, family psychoeducation, family support, and psychopharmacology. CSC is designed to address the needs of individuals experiencing early or first-episode psychosis and engage individuals and their families with appropriate and individualized levels of service.[1]

In 2016, Congress provided funds to SAMHSA to increase the set-aside to 10% with a specification that the funds be used for evidence-based programs addressing first episode psychosis. In December 2016, the 21st Century Cures Act made the 10% set-aside permanent, thus establishing a recurring source of funds to all states and territories for the provision of early psychosis care. This flow of funds through State Mental Health Administrators (SMHAs) allows them to play an important role in the propagation of early psychosis care, including CSC. Beyond funding, SMHAs are also critical in the dissemination of knowledge about first episode psychosis (FEP) and CSC in many states. Building on the evidence for CSC and state support for early psychosis intervention across the country, NIMH established the Early Psychosis Intervention Network (EPINET) in 2018. EPINET is a learning health care initiative

Early Psychosis Intervention Network (EPINET)

- Established in 2018
- Funded by the National Institute of Mental Health (NIMH)
- Comprises eight regional hubs, over 100 CSC programs in 17 states, and the EPINET National Data Coordinating Center (ENDCC)
- Links early psychosis clinics through standard clinical measures, uniform data collection methods, data sharing agreements, and integration of client-level data across service users and clinics
- Clients and their families, clinicians, health care administrators, and scientific experts collaborate within EPINET to improve early psychosis care and conduct large-scale, practice-based research

1 Heinssen R, Goldstein A, Azrin S. Evidence-based treatments for first episode psychosis: components of coordinated specialty care. Bethesda; 2014. https://www.nimh.nih.gov/health/topics/schizophrenia/raise/evidence-based-treatments-for-first-episode-psychosis-components-of-coordinatedspecialty-care.shtml

designed to advance evidence-based practices, standard clinical assessment, data analysis, and stakeholder involvement in promoting practice-based research for early psychosis care (see sidebar on previous page for more on EPINET).

This report provides an overview of CSC programs across the United States and the role of SMHAs in the development and operation of these programs. Each of the SMHAs and their staff were asked to complete an online survey regarding their use of MHBG set-aside funds for evidence-based programs addressing first episode psychosis. This Snapshot complements other EPINET products by providing an overview of the larger CSC community within which EPINET operates. This Snapshot is the fourth in a series. Previous editions were funded by SAMHSA and published by NASMHPD in 2016, 2017, and 2018. As SAMHSA oversees the distribution and implementation of MHBG set-aside funds, previous editions of the Snapshot focused on the state administration of MHBG 10% Set-Funds for early serious mental illness (ESMI). This current report examines more broadly the provision of CSC across the United States with additional focus on state intentions regarding funding CSC care and program collection of client data within specific domains and measures.

Methodology

This Snapshot is the result of a two-part process. The first part was a survey of states, eliciting state-level data and a list of CSC programs within the state that serve individuals experiencing FEP or clinical high risk (CHR) for psychosis. The research team asked the states to complete program-level data for each CSC program. Next, the research team contacted the individual CSC programs to review and confirm program data and to complete any missing parts of the program profile.

The research team developed the state survey using Alchemer, an online survey data collection tool. Some survey questions were based on items included in prior editions of the Snapshot, as well as questions seeking to elicit how states are using the influx of funds from the MHBG and other federal sources for FEP programming. Survey answers were pre-populated using information from prior versions of the Snapshot and from SAMHSA's treatment locator. The research team emailed known FEP contacts in each state a unique link to their state's pre-filled survey. If the email bounced, the team attempted to reach the state planner, and if necessary, the commissioner. Follow-ups were conducted regularly to encourage a high response rate. Initial contact was made in August/September of 2021. The full survey can be accessed at https://survey.alchemer.com/s3/6499921/FEP-Snapshot-Survey-August-2021-for-SMHAs.

Once states responded, the research team reached out to all CSC programs for which an email address was available. In cases where the state had not provided contact information, the team attempted to locate contact information online. In total, 116 of the 345 CSC programs contacted responded to the request to review and complete information about their program. The research team removed those programs that the state identified as not delivering CSC. These included 13 programs in Missouri, which the state identified as delivering ACT, and one program in Vermont, which is a residential program and does not meet the NIMH-defined criteria for delivering CSC.[2]

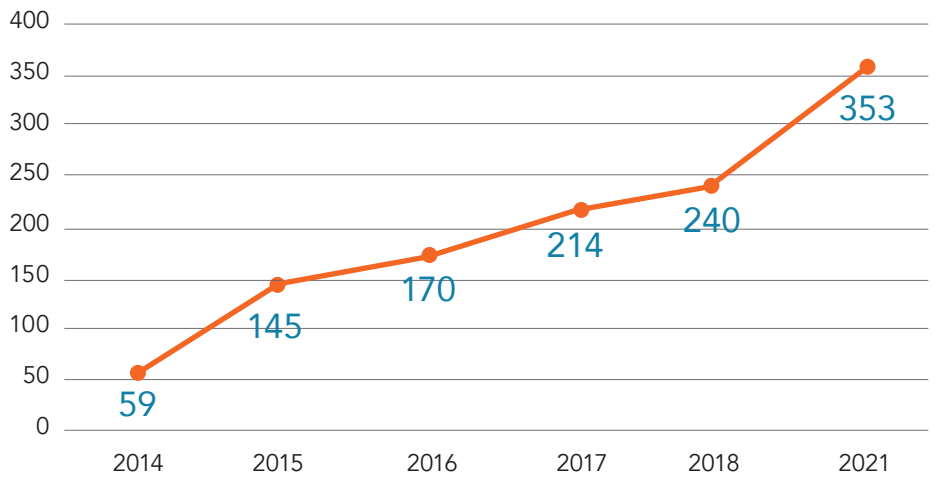
2 Heinssen R, Goldstein A, Azrin S. Evidence-based treatments for first episode psychosis: components of coordinated specialty care. Bethesda; 2014. https://www.nimh.nih.gov/health/topics/schizophrenia/raise/evidence-based-treatments-for-first-episode-psychosis-components-of-coordinatedspecialty-care.shtml

The research team then compiled this information at two levels: the state level and the program level. At the state level, the team assembled the following data: number of CSC programs, the number of clients served in all CSC programs within the state, state funding for CSC, state intentions for additional 2021 MHBG funding, state initiatives with the Medicaid agency and private insurers in their state to increase funding for CSC, use of an intermediate entity to administer CSC programs, and state requirements for data collection. The team also incorporated the number of CSC programs in 2014-2018 extracted from previous Snapshots (2014-2015 data have not been previously published); the number of CSC clients served, MHBG funding, and additional state funding for CSC in 2016-2018 (earlier data not available) extracted from previous Snapshots; and MHBG set-aside funding by state for 2019-2022 downloaded from the SAMHSA website.[3]

At the program level, the team assembled data on: CSC model, age range the program serves, maximum duration of untreated psychosis (DUP), program components, and standardized measures collected by the program. Information on the number of clients served was aggregated to the state level.

CSC Clinics and Clients Served over Time

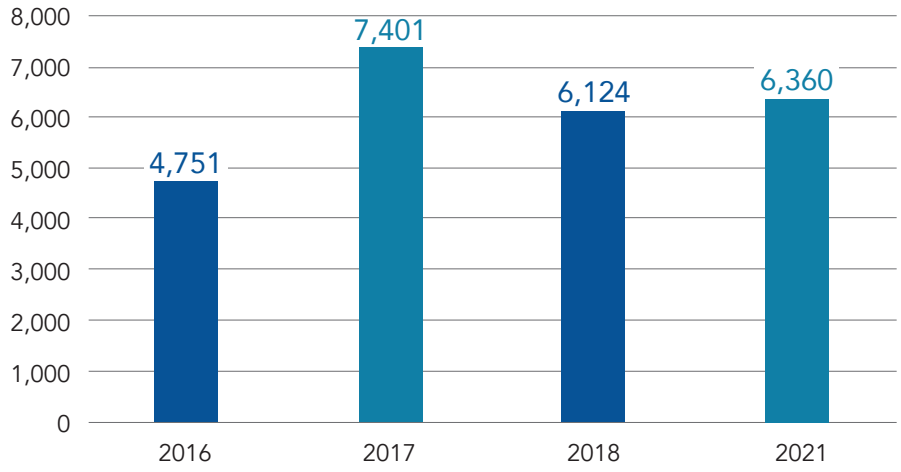
Figure 1. Number of CSC Programs



The number of CSC programs has increased every year the Snapshot has been produced. Starting at 59 programs in 2014, just as the MHBG 5% set-aside for early psychosis had been announced, the number of CSC programs increased to 145 programs in 2015 and 170 programs in 2016, by which time the 5% set-aside had been increased to 10% and established as a permanent addition to the MHBG, providing a source of funding for CSC programs in all states and territories. As awareness of CSC spread among states, the number of programs increased to 214 in 2017 and 240 in 2018. Finally, after three more years, in 2021, the number of CSC programs reached 353. Forty-eight states, the District of Columbia, and Puerto Rico have CSC programs. In several states, treatment in a CSC program is now available either statewide or across most of the state.

3 SAMHSA Grant Awards by State. Substance Abuse and Mental Health Services Administration. https://www.samhsa.gov/grants-awards-by-state [accessed 4/1/2022].

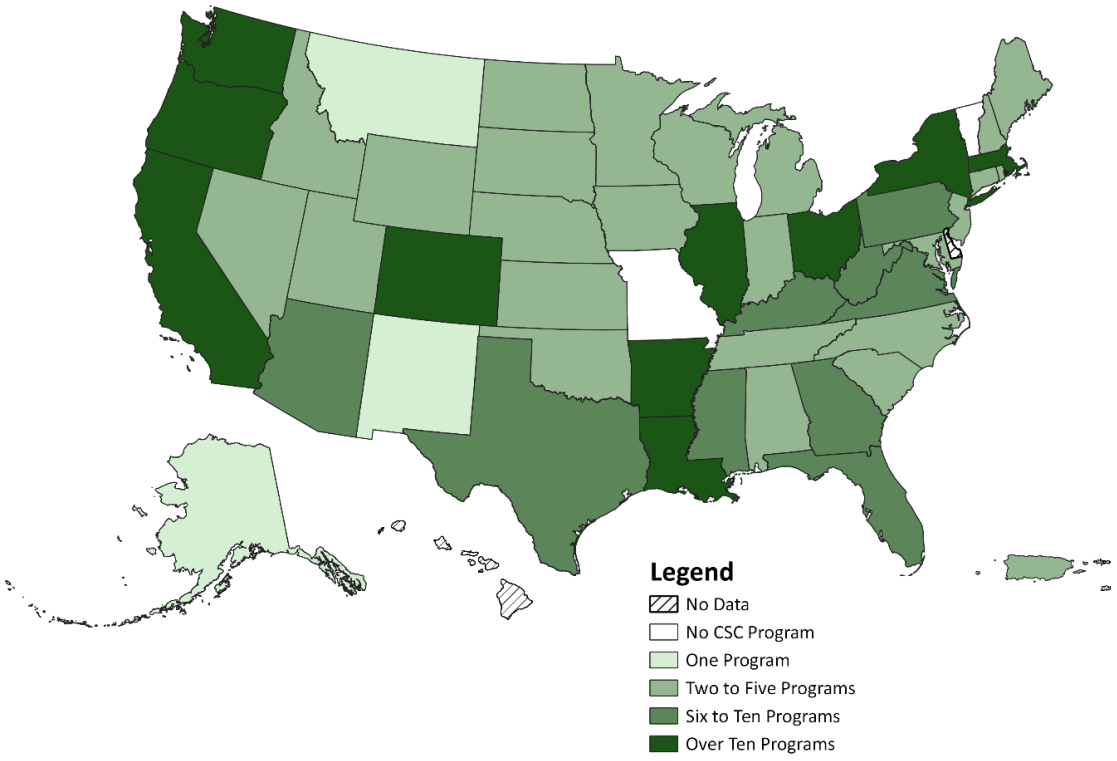
Figure 2. Number of Clients Served in CSC Programs*



* The number of clients served represents data only from states and programs that responded to Snapshot survey.

The number of clients served in CSC programs nationwide has varied over time. Data from states and programs that responded to the Snapshot Survey showed a reported total of 4,761 clients served in 2016, up to 7,401 clients served in 2017, before dropping to 6,124 clients served in 2018. In 2021, states reported serving 6,360 clients in CSC programs. The drop-off reported after 2017 is most likely due to data quality issues and does not reflect a reduction in the number of people served in CSC programs after that year. One primary reason for the peak in 2017 may be that several programs in California appear to have reported client totals that included all treatment for transition age youth, not just CSC. In the most recent reporting year, those programs reported only CSC clients, leading to the total reported number of clients served in California to drop from 2,601 in 2017 to 1,110 in 2021. In addition, the 2021 total may understate the total number of clients that received CSC treatment, as several states that reported in 2018 did not report in 2021, including Kansas, New Jersey, North Carolina, Texas, and Utah. These five states served a total of 576 clients in CSC programs in 2018.

Map 1. Number of CSC Programs by State

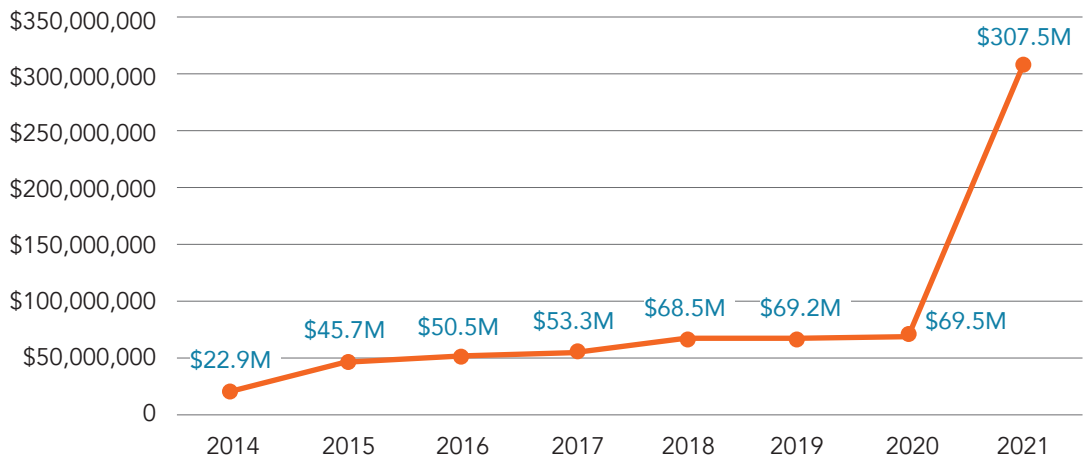


CSC programs are widespread across all regions of the country. States that have funded multiple programs are also found in all regions of the country. This widespread placement of programs demonstrates the evolution of CSC from a primarily researcher-led treatment modality to a type of treatment widely available in community mental health centers (CMHCs). Prior to the 10% set-aside and, even more so, prior to the RAISE study, CSC programs were located only in areas in which researchers at a local university had secured the funding to study this new treatment modality. Examples include STEP in Connecticut, the EARLY program in New Mexico, and areas where state governments pushed forward the new treatment modality, such as EASA in Oregon.

Several states have moved beyond providing CSC in a limited number of sites in the largest cities in the state and now provide CSC throughout much of their state, such as in Oregon and New York. In California, most counties now provide CSC or are in the process of starting a CSC program. These programs are supported by significant funding from California's Mental Health Services Act, which requires the implementation of prevention and early intervention programs. Since 2018, Illinois, Ohio, Texas, Colorado, Massachusetts, and Washington have begun initiatives to spread CSC programs across their state.

Investment in CSC over Time

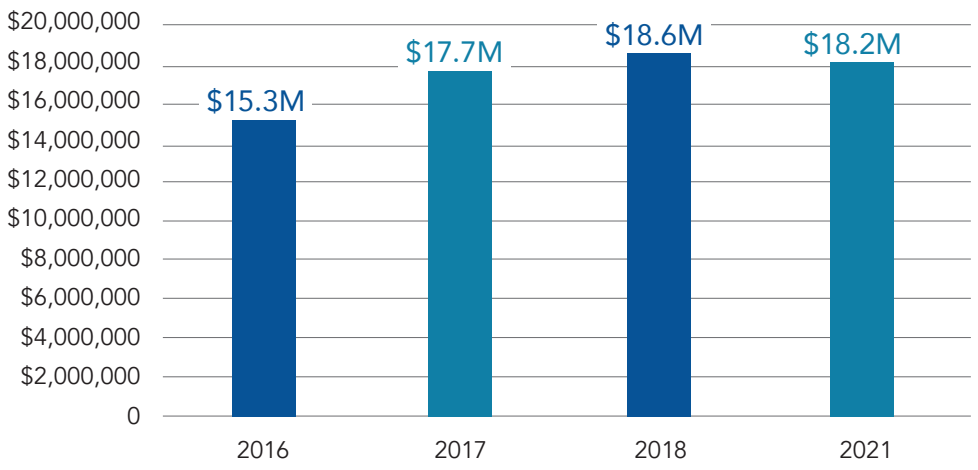
Figure 3. Federal Investment in Early Psychosis Programming since 2014



The MHBG set-aside for early psychosis has remained an important source of funding for many CSC programs since 2014. From 2015 through 2017, the set-aside increased slowly from $45.7M to $53.5M. In 2018, this increased more sharply to $68.5M, increasing only slightly to $69.5M by 2020. In 2021, the MHBG increased to $82.5M. In addition, a supplement to support states during the COVID-19 pandemic temporarily doubled the MHBG. These COVID supplemental funds must be expended by 2022. Finally, the American Rescue Plan (ARP) provided an additional supplement to the MHBG (to be expended over 5 years), of which $142.5M go to the 10% set-aside, leading the total funding of the 10% set-aside in 2021 to $307.5M.

Beyond the MHBG 10% set-aside funding for early psychosis shown in the chart above, some states use other federal grant funding (such as SAMHSA's Healthy Transitions grants) to fund early psychosis services. In addition, many early psychosis programs bill Medicaid.

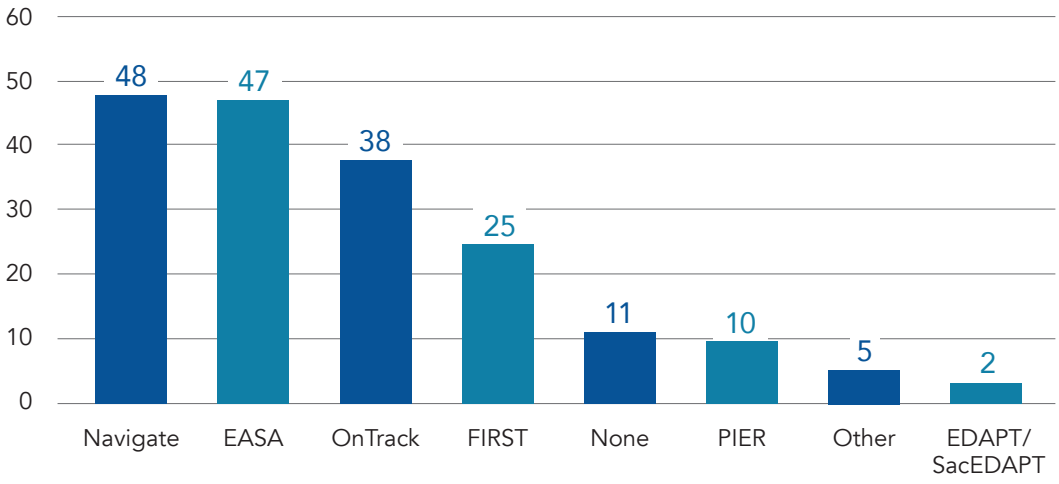
Figure 4. Additional State Funding for CSC over Time



State funding for CSC has been important since before the set-aside. Many states do not provide additional funding for CSC and, of those that do, only a few provide substantial additional funds. Across the time period captured by the Snapshot, Oregon, New York, California, Virginia, and Maryland have provided financial support to CSC programs that exceeds MHBG set-aside funding. Other states provide smaller amounts, with amounts often varying significantly from year to year. The Snapshot captured increases in state funding of CSC from $15.3M in 2016, to $17.7M in 2017, and $18.6M in 2018. The decrease shown in 2021 is most likely due to New York not reporting funding data and Oregon reporting partial data.

Description of US CSC Programs

Figure 5. CSC Programs Models*



* The lower number of programs represented in this figure is due to item response rate.

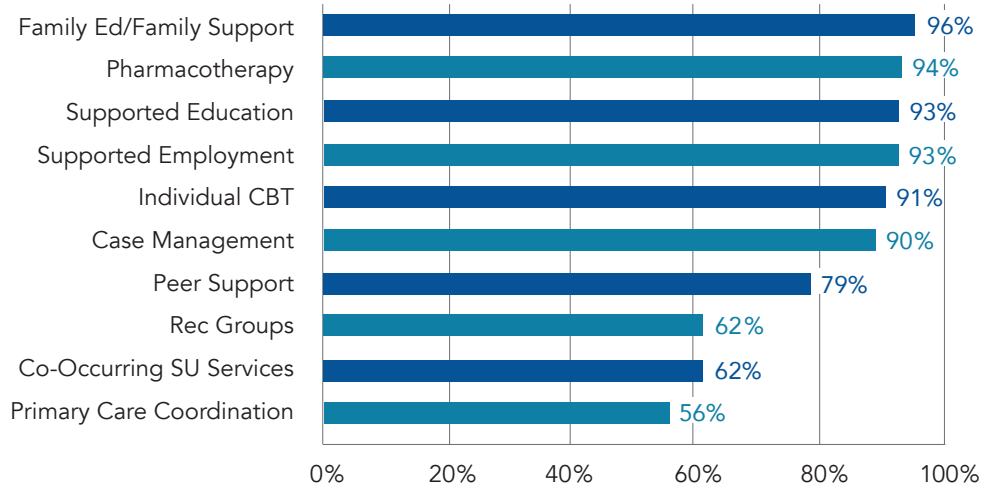
The most commonly reported CSC model was NAVIGATE with 48 programs (25.7%), followed by EASA with 47 programs (25.1%). Thirty-eight programs (20.3%) followed the OnTrack model, and 25 programs (13.4%) followed the FIRST model. Ten programs (5.3%) followed the PIER model and three programs (1.6%) followed the EDAPT model. Five programs (2.7%) identified another model. These other models included two programs in Ohio following the EpiCenter model, the STEP model in Connecticut, the Early Psychosis Intervention Clinic (EPIC) model in Montana, and the Evolve model in Georgia. Finally, eleven programs (5.9%) indicated that they do not follow any specific CSC model. CSC programs reporting that they do not follow a specific model include several long-standing programs, including Early at the University of New Mexico, UCSF PATH, PERC at the University of Pennsylvania, and CARE at UCSD.

Table 1. CSC Model by Number of States

CSC Model	# of states with model
NAVIGATE	**16**
OnTrack	**11**
EASA	**6**
PIER	**3**
FIRST	**2**
EDAPT	**1**

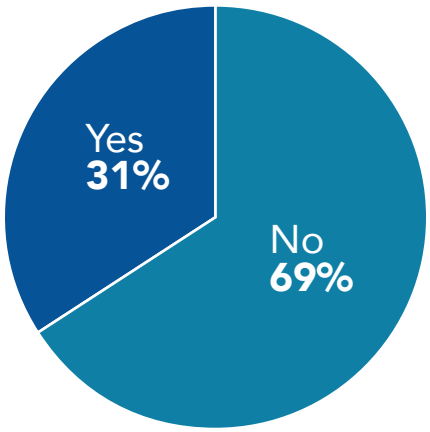
We can also consider the geographic spread of CSC models (see Table 1). NAVIGATE is the most commonly reported model, followed by OnTrack, EASA, PIER, FIRST and EDPAT. PIER is present in California (including the five CSC programs in Los Angeles County), Maine and Utah. FIRST is present in Ohio and Illinois, the latter having adopted the model for its statewide rollout of CSC. EDAPT is only present in California.

Figure 6. Top Ten CSC Program Components



Of the 211 CSC programs that provided information about the services they provide, over 90% of programs provide family education/family supports, pharmacotherapy, supported education, supported employment, and individual CBT (cognitive behavioral therapy). Just less than 90% of CSC programs provide case management and over three-fourths of CSC programs provide peer support. Sixty-two percent of programs provide psychoeducation and co-occurring substance use services and a little over half of programs provide primary care coordination.

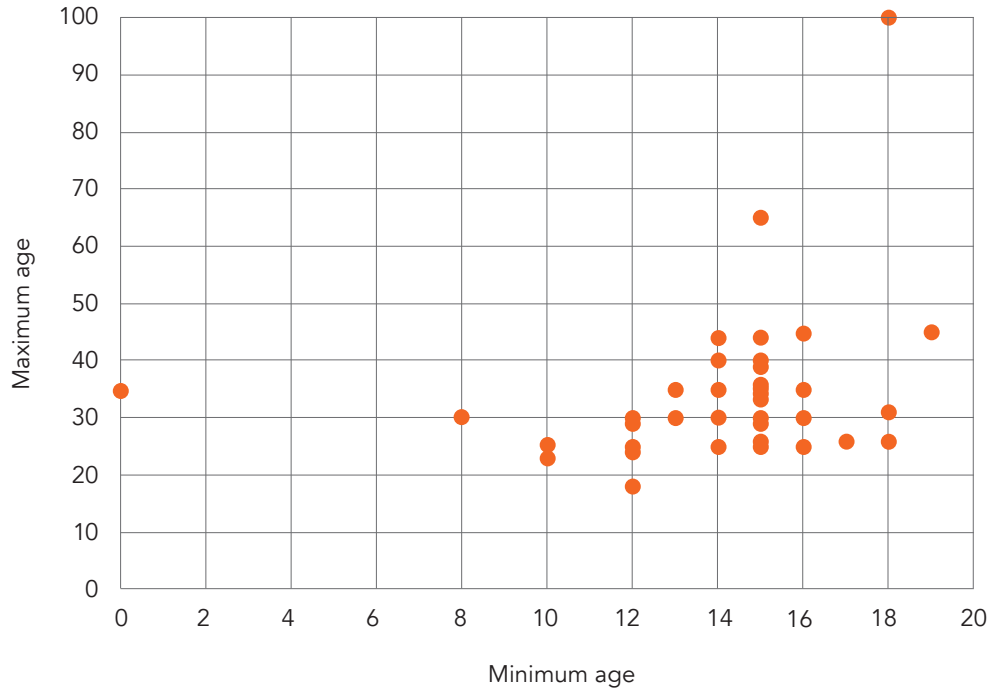
Figure 7. Programs Accepting CHR Clients



The majority (69%) of CSC programs report not accepting clients with CHR into their programs. Twenty-nine states responded to the question of whether they restrict or encourage programs to accept CHR clients. Only eight states indicated that they restrict states from accepting CHR clients. Nine states indicated that they do encourage programs to accept CHR clients. Several states indicated that they leave eligibility criteria for the provider to determine. One state indicated that they believed that the 10% set-aside could not be used for CHR clients and use state funds to provide services to such clients. The MHBG cannot be used for CHR clients as SAMHSA specifies in the *FFY 2022-2023 Block Grant Application for the Community Mental Health Services Block Grant (MHBG) Plan and Report* that "MHBG funds cannot be used for primary prevention activities. States cannot use MHBG funds for prodromal symptoms (specific group of symptoms that may precede the onset and diagnosis of a mental illness) and/or those who are not diagnosed with a SMI."[4]

4 Substance Abuse and Mental Health Services Administration. (2022). FFY 2022-2023 Block Grant Application Community Mental Health Services Block Grant (MHBG) Plan and Report. Accessed on October 11, 2022 at https://www.samhsa.gov/sites/default/files/grants/fy22-23-block-grant-application.pdf.

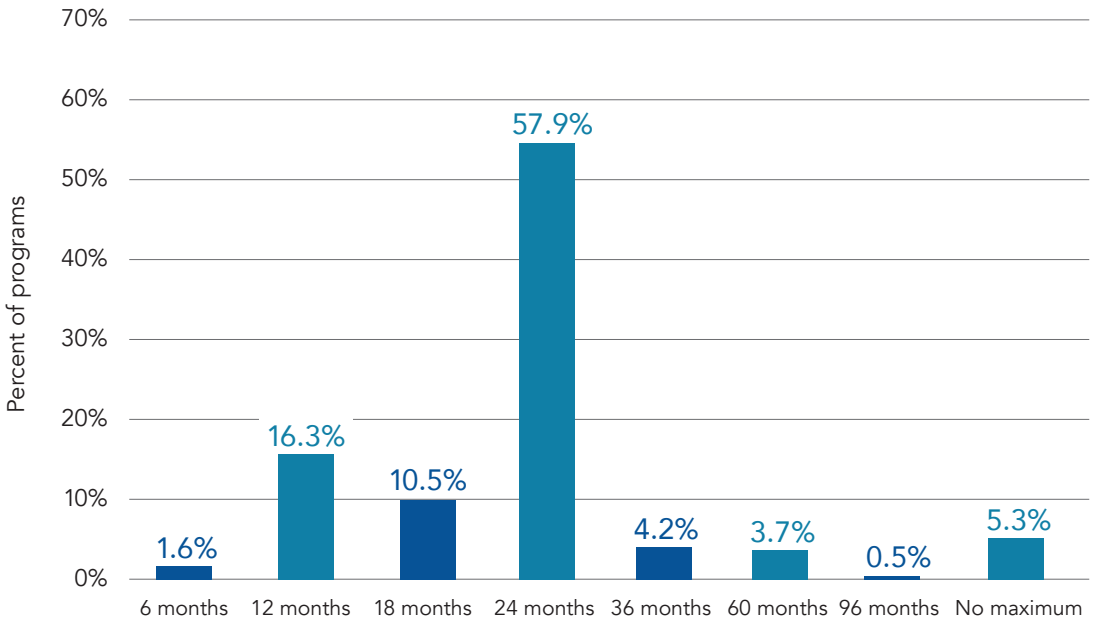
Figure 8. Age Range Criteria of CSC Programs*



* Orange dots in the graph indicate CSC programs.

CSC programs establish different age ranges as inclusion criteria for clients. The modal (and median) minimum age served by CSC programs is 15, while the modal (and median) maximum age is 30. One program indicated they do not have a minimum age (shown above as a minimum age of 0) and one program has a minimum age of eight. One program indicated that they do not have a maximum age (shown above as a maximum age of 100), while three programs indicated a maximum age of 65. Seventy-one percent of CSC programs had a minimum age of 15 or 16. Fifty-eight percent of CSC programs had a maximum age of 30 or 40, while 73.1% of CSC programs had a maximum age between 30 and 40 (inclusive).

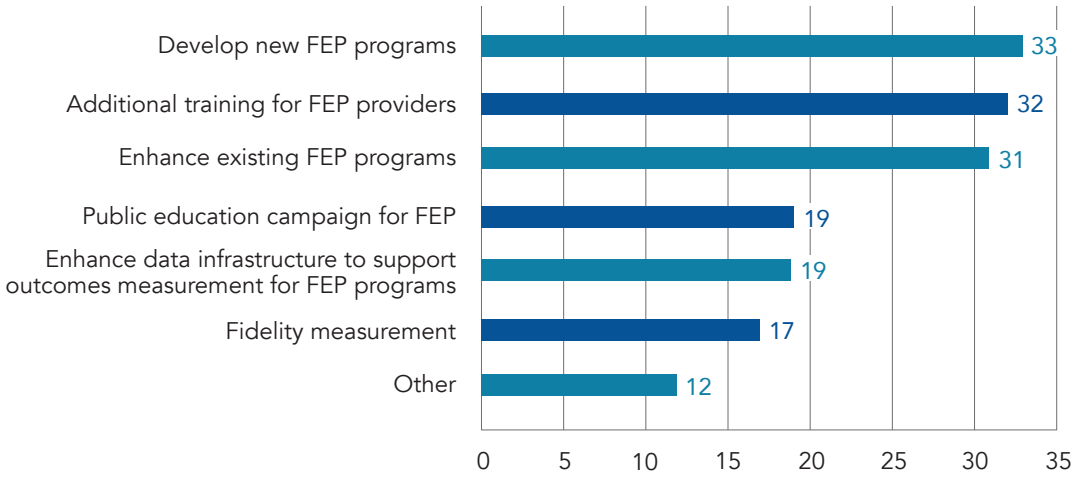
Figure 9. Maximum Allowable Duration of Untreated Psychosis (DUP) among CSC Programs



One-hundred ninety programs reported the maximum duration of untreated psychosis (DUP) that a client could have when they entered the program. Over half of programs have a maximum DUP of 24 months, with 84.7% of programs having a maximum DUP of 12 to 24 months. 5.3% of programs indicated that they do not have a maximum DUP and 4.2% of programs indicated that they have a maximum DUP of five years or more. Only 1.6% of programs had a maximum DUP of less than 6 months.

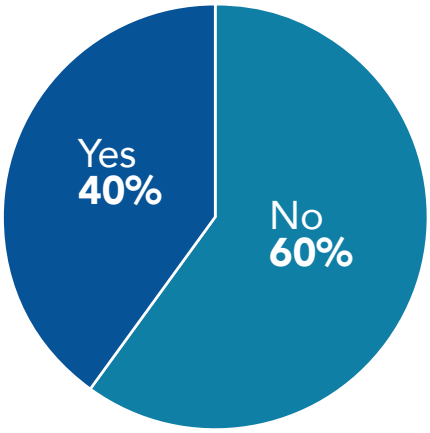
State Involvement in the Administration of CSC Programs

Figure 10. State Intentions for Additional 2021 10% Set-Aside Funding



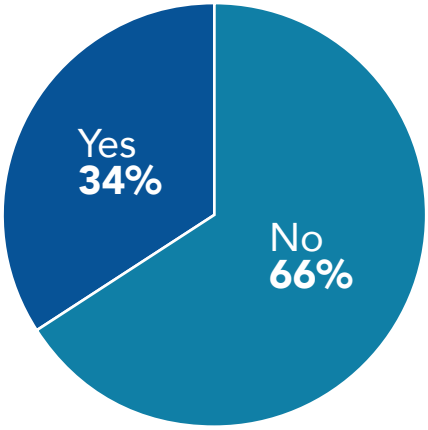
Forty-two states reported their intentions regarding the 2021 supplemental funding. The most common response of states regarding their intentions of how to spend the supplemental MHBG 10% set-aside funding were to develop new FEP programs (33 states), provide additional training for FEP providers (32 states), and enhance existing FEP programs (31 states). Nineteen states indicated that they would use the supplemental funding for a public education campaign for FEP or to enhance data infrastructure to support outcomes measurement for FEP programs. Seventeen states plan to use the supplemental funding to support fidelity measurement among FEP programs. Finally, twelve states had other intentions for the supplemental funding. Some of these other intended uses for the supplemental funding include: workforce retention efforts, expanding triage/assessment services statewide and facilitating referrals to FEP programs, hiring an Early Serious Mental Illness (ESMI) Medical Director, funding an ESMI Center for Excellence, improving Spanish-language competencies of FEP programs, working with an intermediate entity to develop a bundled rate and design a step-down protocol for FEP programs, and working with tribal leaders to adapt CSC for use in tribal and rural settings.

Figure 11. States with Intermediate Entity to Administer CSC Programs



Of the 43 states that reported whether they work with an intermediate entity in the administration of FEP services in their state, the majority of states (26 or 60%) indicated that they do not. Of the 17 (40%) states that do work with an intermediate entity, 14 states contract with a university, two states contract with a CMHC, and one state indicated that the intermediate entity varies by region within the state. Among these 17 intermediate entities, 15 provide technical assistance to CSC programs within the state and 11 collect data from CSC programs.

Figure 12. States Working to Build Team-Based Medicaid Rate*



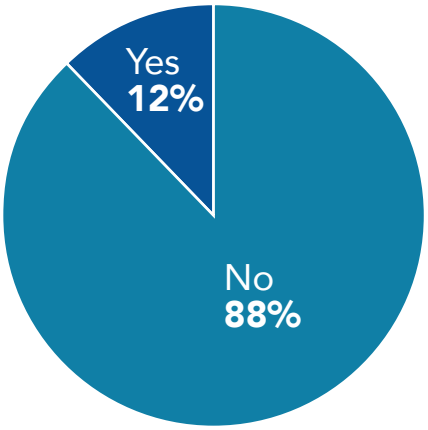
* Number of states responding = 44

Most CSC programs use a blend of Medicaid, commercial insurance, and other subsidies for revenue. However, many CSC services, such as supported employment and education, have not traditionally been reimbursed by health insurance plans. Supporters of CSC have advocated for a consistent national reimbursement method that would allow people with early psychosis who have Medicaid and/or commercial insurance the ability to access these services.[5] Of the 44 states that responded, 15 (34%) are working, or have worked, with their state Medicaid

5 Dixon, L. (2016). What it will take to make Coordinated Specialty Care available to anyone experiencing early schizophrenia: Getting over the hump. *JAMA Psychiatry*, 74(1), 7-8.

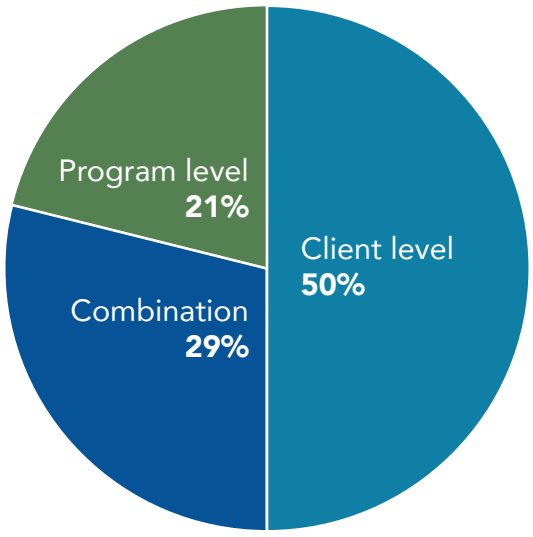
agency to develop a bundled rate that would collectively reimburse the providers involved on the CSC team to better reimburse for FEP services. Five states said that discussions with the Medicaid agency are ongoing. Utah and Virginia indicated that such discussions are contemplated, but not ongoing. Missouri and Rhode Island indicated that they are able to bill under their state's billing rate for ACT. New Mexico indicated that a bundled rate for CSC has been included by their legislature under Medicaid ACT programs. Per member per month (PMPM) case rates are a strategy to provide bundled rates. Pennsylvania indicated two CSC programs receive a PMPM case rate under their state's 1915b Medicaid waiver and other programs are exploring this option.

Figure 13. States Working with Private Insurers to Develop Case Rate for CSC



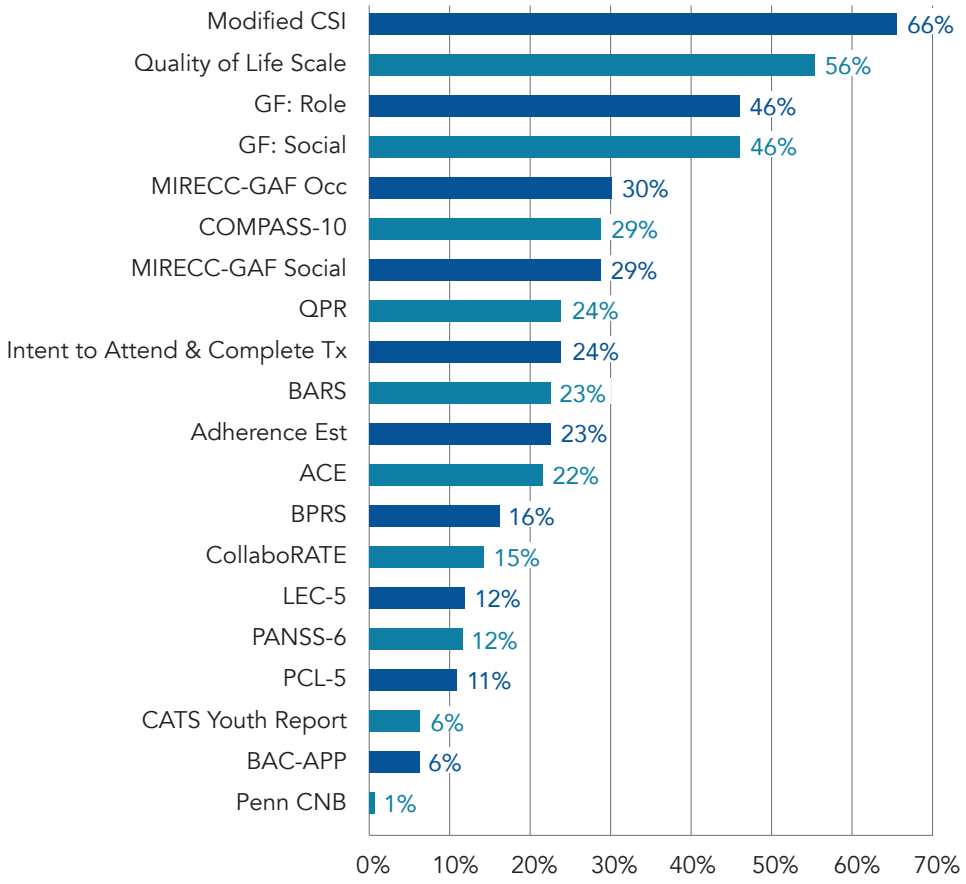
Fewer states are working with private insurers to develop a case rate for CSC, with only five states indicating action in this domain. All but one of these states is also working with their state Medicaid agency to develop a bundled rate for FEP services. Connecticut and Michigan indicate that they are in talks with individual insurers. Utah says that the SMHA is helping the CMHC operating their CSC programs to get their prescribers paneled by insurers. In Illinois, the Department of Insurance is working on legislation to bundle FEP services.

Figure 14. Aggregation Level of Required Data Reporting by CSC Programs to State



Half the states that reported the level of aggregation for data reporting require CSC programs to report data to the state at the client level. Only nine (21%) states require CSC programs to report data aggregated to the program level. Twelve (29%) states require CSC programs to report some data to the state at the client level and some at the program level.

Figure 15. Standardized Measures Collected by CSC Programs



One hundred seventy-one programs collect any of the standardized measures that comprise the Core Assessment Battery (CAB). Eighteen states require the reporting of one or more of these measures. Two-thirds of programs collect the Modified CSI and over half of programs collect the Quality of Life Scale. Slightly less than half of programs collect the Global Functioning: Role Scale and the Global Functioning: Social Scale. Less than one-third of programs collect components of the MIRECC-GAF and the COMPASS-10, and between one-fifth and one-fourth of programs collect the QPR, the Intent to Attend & Complete Treatment, BARS, the Adherence Estimator, and the ACE Questionnaire. Lower percentages of programs collect the remaining measures.

Discussion and Conclusion

The Snapshot provides a unique opportunity to look at the current landscape of U.S. first episode psychosis programs. CSC programs continue to proliferate across the country and expand the reach of services for people with early psychosis. The number of CSC programs increased nearly six times between 2014 to 2021 (498% increase), and publicly funded CSC programs serve tens of thousands of adolescents and young adults each year. The growth in federal investment in CSC has coincided with this dramatic expansion of needed services, highlighting the role of MHBG set aside funds for supporting the establishment of first episode psychosis programs in nearly every U.S. state and territory.

The Snapshot also provides perspectives of State Mental Health Authorities (SMHA) who allocate the MHBG set aside funds in U.S. states and territories. The additional federal support has allowed states the option to build on their existing programs, through activities such as expanding training, but also plan for developing infrastructure for new FEP programs.

Further, because this is the fourth iteration of the Snapshot, not only does this allow for an assessment of longitudinal data on the growth of these programs over time, but it highlights the characteristics of first episode programs and shows their similarities (e.g., services provided, populations served) and diversity (e.g., models used and capacity for number of clients). Barriers still remain for those accessing services. Diversity of funding streams to increase the use of Medicaid and private insurance support will be essential to sustainability in program infrastructure and reimbursement for all CSC service components, which remain critical sources of support for young people and their families.

Although we reached out to all 345 CSC programs across the country, we received response from 114 programs, which limited our ability to have a comprehensive view of program characteristics across all U.S. CSC clinics.

We are hopeful that future iterations of the Snapshot will show a similar growth in the number and availability of first episode psychosis programs. Administrative and programmatic information from the Snapshot complements our understanding of the service capacity, financing, and contextual factors that may play a role in treatment quality, effectiveness, and growth of CSC programs across the country.