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ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

Continuity of Care Services Following Coordinated Specialty Care: An Environmental Scan

Prepared for
the Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health & Human Services

by
Westat

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CONTINUITY OF CARE SERVICES FOLLOWING COORDINATED SPECIALTY CARE: AN ENVIRONMENTAL SCAN

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ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ACT	Assertive Community Treatment
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BeST	Best Practices in Schizophrenia Treatment
CBTp	Cognitive Behavioral Therapy for Psychosis
CCBHC	Certified Community Behavioral Health Clinic
CMHC	Community Mental Health Center
COVID-19	Novel Coronavirus 2019
CSB	Community Service Board
CSC	Coordinated Specialty Care
CTI	Critical Time Intervention
CTT	Continuous Treatment Team
DBHDD	George Department of Behavioral Health and Developmental Disabilities
DBT	Dialectical Behavior Therapy
EASA	Early Assessment and Support Alliance
EIP	Early Intervention in Psychosis
EPINET	Early Psychosis Intervention Network
FEP	First Episode of Psychosis
HCBS	Home and Community-Based Services
IAPT	Improving Access to Psychological Therapies
ILP	Independent Living Program
IPS	Individual Placement and Support
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer (or Questioning)
LIGHT-ETP	Listening, Inspiring and Guiding Healthy Transitions Early Treatment Program
MHBG	Mental Health Block Grant
MMHPI	Meadows Mental Health Policy Institute
NASMHPD	National Association for State Mental Health Program Directors
NICE	U.K. National Institute for Health and Care Excellence
NIMH	National Institute of Mental Health
NRI	NASMHPD Research Institute

PEI	Prevention and Early Intervention
PEPP	Prevention and Early Intervention Program for Psychosis
PROMISE	Promoting Optimal Mental Health for Individuals through Supports and Empowerment
RAISE	Recovery After an Initial Schizophrenia Episode
RAISE-ETP	RAISE Early Treatment Program
REACH	Raising Early Awareness Creating Hope
SAMHSA	Substance Abuse and Mental Health Services Administration
SEE	Supported Employment and Education
SMHA	State Mental Health Authority
SOC	System of Care
STEP	Specialized Treatment Early in Psychosis program
TAY	Transition Age Youth
TBS	Therapeutic Behavioral Services
TIP	Transition to Independence Process
U.K.	United Kingdom
U.S.	United States
YATT	Young Adult Transition Team

I. INTRODUCTION

A legitimate concern is that specialized first episode programs may be offering an intensive treatment that is no longer available after discharge from the first episode program…Just referring to other agencies may not be enough; we have to determine who needs what level of care. -Addington & Addington, 2008

Through the careful efforts of large-scale trials in the United States (U.S.) and around the world, specialized early intervention in psychosis (EIP) services are now understood to substantially improve post-onset outcomes for individuals experiencing a first episode of psychosis (FEP; e.g., Correll et al., 2018; Kane et al., 2015; Nordentoft et al., 2014; Dixon et al., 2018). In the United States, these services are frequently referred to as coordinated specialty care (CSC), and stem from the Recovery After an Initial Schizophrenic Episode (RAISE) project. RAISE involved two separate components: an observational study in New York and Maryland (Dixon et al., 2015), and the RAISE Early Treatment Program study, a 34-site randomized trial of early intervention services, which established the effectiveness of CSC services as compared to usual care in community-based settings (Kane et al., 2015). As typically implemented, CSC is a team-based intervention for FEP that combines well-established evidence-based treatments, including assertive case management, psychotherapy, supported employment and education (SEE) services, family education and support, and low doses of antipsychotic medications, and delivers these within a shared decision making framework. These services are also closely coordinated with primary health care and when appropriate, the individual's close friends and family members are also involved as participants in treatment.

Researchers around the world--including Canada (Addington & Addington, 2008), the Netherlands (Linszen, Dingemans & Lenior, 2001), Australia (Yung, 2012), Denmark (Secher et al., 2014), Hong Kong (Chang et al., 2017) and the United Kingdom (U.K.; Gafoor et al., 2010)--have noted the challenge of sustaining gains achieved in early intervention programs once clients are no longer receiving intensive services. This finding has motivated several extension studies, in which clients' post-discharge trajectories were rigorously examined. These extension trials suggest that participants who received services for a longer number of years (showed lengthier remission of symptoms (Malla et al., 2017; Chang et al., 2015), better functioning and reduced depression (Chang et al., 2015), higher satisfaction with services, and better alliance with their provider (Albert et al., 2017). The degree that gains can be sustained may depend largely on the intensity, focus, and duration of support received relative to a client's needs and desires.

Within the United States, early intervention services greatly expanded following the Consolidated Appropriations Act of 2014, a congressional mandate that included a 5 percent supplement and set-aside in the Mental Health Block Grant (MHBG)

administered by the Substance Abuse and Mental Health Services Administration (SAMHSA). The MHBG 5 percent set-aside required states to direct the additional funds--5 percent of their MHBG allocation--to support evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders. Congress subsequently increased the MHBG set-aside to 10 percent in 2016, making the set-aside permanent through the 21st Century Cures Act. Fueled by block grant set-aside funds, CSC programs have proliferated in the United States; a national survey of CSC programs in 2018 found that approximately 70 percent of programs started serving clients in 2014 or later (Westat, 2019). Lists of CSC programs compiled by the National Association for State Mental Health Program Directors (NASMHPD) and the Early Assessment and Support Alliance (EASA) program directory[1] identify more than 250 CSC programs nationally.

As many of these CSC programs mature, teams are increasingly faced with key decisions, including determining **optimal program length**, what can be done to **facilitate a transition** when clients leave the program, and what may be the **most appropriate services** for ongoing care. In their initial document defining CSC programs, National Institute of Mental Health (NIMH) scientists described CSC as a model in which clients receive services for a period of 2-3 years, and then are transitioned into other ("routine") services and programs, namely:

> The team provides a critical time intervention [CTI] rather than a source of services for people well along in their recovery. Clients transition from the team to routine services as soon as clinically appropriate. The team follows up with discharged clients and with post-discharge providers as appropriate to help assure a smooth transition to routine community services (Heinssen, Goldstein & Azrin, 2014).

SAMHSA has supported the development of two additional technical assistance documents, which provide an overview of relevant research on transition (Jones, 2016) and recommendations for clinicians to promote successful transitions (Pollard & Hoge, 2018). Both reviews draw on the experiences of relatively well-established programs in the United States, including guidelines outlined by EASA in Oregon; OnTrackNY in New York; Felton PREP (now known as (re)Mind™) in the San Francisco area; OASIS in Chapel Hill, North Carolina; the Specialized Treatment Early in Psychosis (STEP) program in Connecticut, and the Best Practices in Schizophrenia Treatment (BeSt) Center in Ohio.

Both reviews also note a critical issue that can only partially be mitigated through the work of CSC teams: There is a lack of skilled providers and evidence-based services within the broader mental health system to serve young adults following participation in a CSC program. For example, the frontline evidence-based therapeutic intervention for psychosis--Cognitive Behavioral Therapy for Psychosis (CBTp)--is widely unavailable outside of CSC in the United States (Kimhy et al., 2013). Pollard and Hoge (2018) note that a "critical step" in transitions is to educate the receiving providers both about the

[1] See http://www.easacommunity.org/national-directory.php.

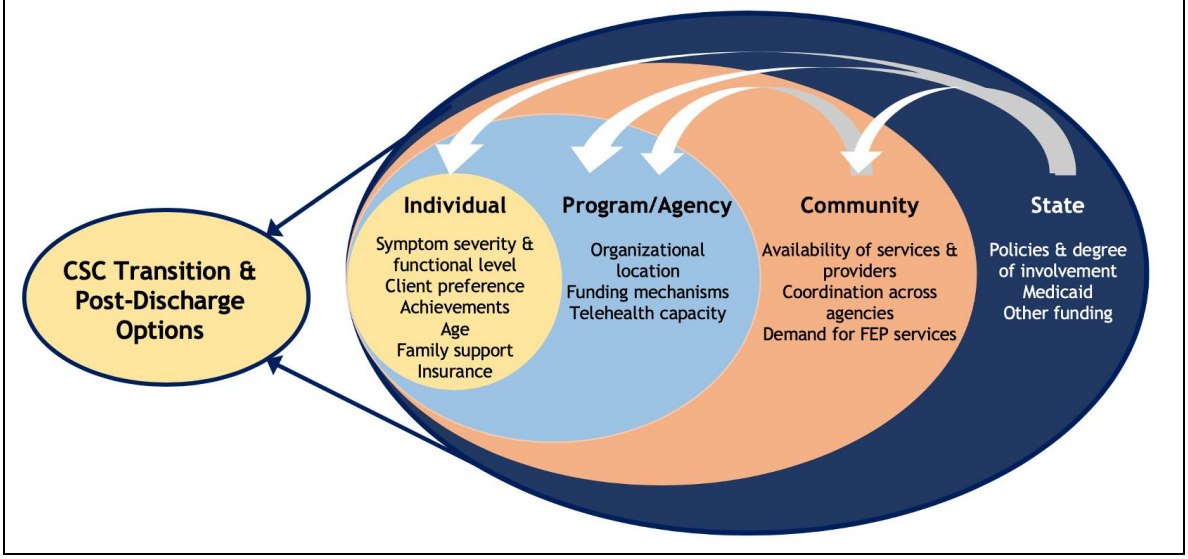
nature of CSC services and the needs of each referred client, as differentiated from individuals who have more profound disability associated with their illness than FEP clients. Echoing this, Goldman (in press) notes that the CSC model was intended to bring together evidence-based services and provide these through a team format, yet these same program components cannot always be found in the broader community. Intensive, team-based care that promotes recovery for younger individuals is rarely available in community mental health settings. Moreover, the public health orientation of CSC, supporting involvement of clients regardless of insurance status or ability to pay, leads to additional discharge challenges related to variable service availability between the private and public sectors.

The availability of referral options is one of the major considerations for transitioning, but it is far from the only factor a program must navigate. Just as accessing care through CSC services has been conceptualized within a socio-ecological framework (Moe et al., 2018), the factors that shape post-CSC service availability and appropriateness can similarly be represented.

Exhibit I-1 identifies many potential state, community, program, and individual-level variables that may influence the transition process.

At the broadest level, State Mental Health Authorities (SMHAs) vary in the degree of involvement and oversight of local programs, including aspects such as the extent to which they impose limits for length of time a client can remain in a CSC program and whether they promote specialty step-down services. Perhaps most critically, every state is different with respect to the array of Medicaid-covered services (Shern et al., 2017). This has bearing on funding for continuation of services, as discussed in Section III-E. States also vary widely both in the amount of Block Grant Set-Aside funds received, as well as state general fund spending on FEP programs and activities (NASMHPD, 2018).

Exhibit I-1. Multiple Levels of Influence on CSC Transition and Post-discharge Options



Even within a single state, communities vary. As previously noted, the most significant of community-level factors relates to the variety and availability of individual providers or programs that are competent to receive and effectively treat young adults completing a CSC program since most programs serving people with severe mental illness are accustomed to individuals with more chronic impairments. Providers, including psychiatrists, may be reluctant to work with clients who have psychosis. In other cases, especially where programs are newer and less outreach has taken place, CSC programs may simply not be aware of community providers who are available to serve clients post-discharge. Communities also differ with respect to demand for CSC services: In a community with more referrals than the program can handle, there is greater pressure to discharge in order to make room for new clients. In contrast, some sites (including in the MHBG 10 Percent Study) have trouble filling their roster and therefore have less pressure to "graduate" clients to other settings. Sites that are not at capacity may be more willing to keep clients for a longer period of time. In rural areas, programs may have limited resources that can be accessed after CSC programs, particularly when compared to an urban-based program.

At the level of the program, one of the key drivers of placement options following a CSC program is the organizational location of the program (i.e., whether the program is free standing or part of a larger community mental health center [CMHC], a hospital, a university, or other setting). Programs that are part of a larger organization may have internal referral mechanisms and may be able to maintain continuity of relationships within the agency and some treatment or support staff. CMHCs also vary with respect to whether they are child-serving, Transition Age Youth (TAY)-serving, adult-focused, or serve clients across age brackets. The organization of programs within an agency can shape whether the same providers can continue to work with a client if they transition to another program within the same CMHC. Agencies also vary with respect to what payment they accept as well as the sources of funding. For example, some states consider university-based programs ineligible for MHBG funds, which in turn can impact whether the program can offer services that are not reimbursed by Medicaid or private insurance.

CSC programs are intended to be highly individualized (Bennett et al., 2014) and consistent with this, the specific strengths and needs of each client should be a primary driver in post-CSC placement decisions (Pollard & Hoge, 2018). Additional work is needed to more closely examine whether current or pre-morbid functioning (such as attending college) predict the nature of post-discharge services. While limited to administrative records, one study from the United Kingdom found having an enduring psychotic illness, such as schizophrenia, schizoaffective disorder and delusional disorder, and a longer duration of treatment in the early intervention program relative to other clients were both associated with discharge to a setting that provides a higher level of care (Ahmed, 2018). There was no effect of gender, ethnicity or geographical location.

Client age can both open and close doors. For clients who are under 25, there may be options to move into TAY programs rather than adult services (i.e., age can open a

service option). On the other hand, if youth-focused interventions are not available, then CSC teams may struggle to find psychiatrists who are both experienced with and willing to take on younger clients with psychosis. Whether clients have family support is an important individual-level consideration in identifying a post-discharge placement in that clients may need assistance in transportation and making and keeping appointments, activities that were previously handled by CSC team staff. Lastly, and quite importantly, client insurance is another major factor that can determine post-CSC options in the United States. As highlighted by an example from an inventory of CSC programs developed by NASMHPD and NASMHPD Research Institute (NRI), a research organization affiliated with NASMHPD (2017):

> At the completion of this period of early intervention, patients will be transferred to a range of ambulatory services *depending on their insurance status* [emphasis added]…Patients who are unable to procure commercial or federal insurance will be transferred to one of the regular ambulatory teams at the Connecticut Mental Health Center, which is the present home of STEP (2017, p. 116).

Insurance is discussed in greater detail in Section III-E.

The Current Study

The increasing number of CSC programs faced with questions related to transitions coupled with the wide range of potential post-discharge placement options led the Office of the Assistant Secretary for Planning and Evaluation (ASPE) to design the current study. The purpose of the Coordinated Specialty Care Transitions Study is to understand the current landscape of existing approaches to continuity of services after discharge in CSC programs in the United States and larger health care system integration efforts that can be used to support these services. Based on an environmental scan and a set of case studies, the overall study has three major objectives:

1. Describe the range of existing approaches to continuity of services after a client participates in a CSC program.
2. Describe the challenges and opportunities in implementing different approaches to continuity of services.
3. Identify ways CSC programs can be better integrated into the existing continuum of care for people with psychosis.

The current report presents the findings from the environmental scan, with the goal to **provide a current picture of what is happening in the United States**; this scan does not include a formal review of the academic literature, although relevant studies are incorporated where appropriate.

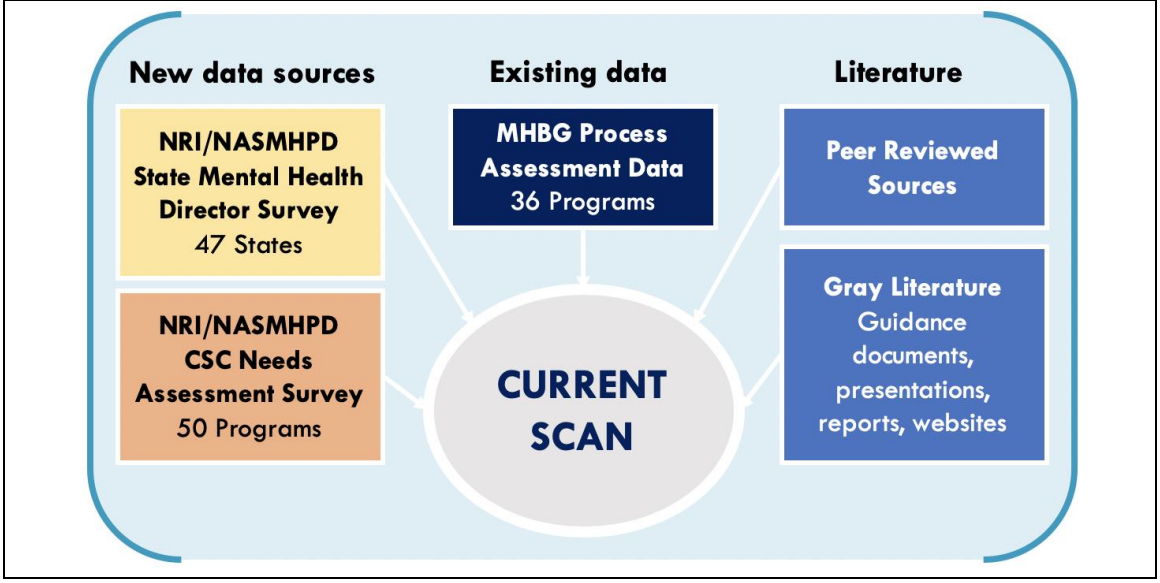
In Section II we describe the sources used in this synthesis. Section III begins with a discussion of terminology related to services received following participation in a CSC program. This is followed by an overview of current models for post-CSC services; how

programs prepare for transitions; and what challenges programs currently identify in working with clients through transitions. The scan concludes in Section III with a discussion of policy issues, and in Section IV, we highlight selected future opportunities and provide a summary.

II. METHODS

This environmental scan synthesizes four sources of information. For the final report, case studies will also be used.

Exhibit II-1. Environmental Scan Sources of Data



A. Peer Reviewed Literature

Studies that examine some aspect of transitions have been conducted under a wide range of circumstances, and primarily outside the United States. They also vary in methodology, depending on the purpose of the study (i.e., to obtain participant perspectives on discharge vs. to compare outcomes between groups that received different lengths of treatment). Given the limited literature base that exists, we chose to incorporate data from studies of all types of designs, and as noted above, this scan does not include a comprehensive review of peer reviewed literature. Rather, we included referenced publications to support the specific topics of focus in this scan. The initial search for relevant articles was conducted using the same set of search parameters as for general online sources, noted below. Additional sources were obtained through references within publications.

B. Gray Literature

As a relatively new topic and one that draws heavily on practitioner experience, the "gray" literature forms a major source of our review. These sources include

organization, agency, state and other websites, guidance documents, presentations, program descriptions, unpublished or yet-to-be published papers, and other similar materials. These documents were obtained through different avenues.

1. We repeated a series searches using Google to locate a wide set of resources. In these searches, text within the quotations must appear exactly as written; phrases separated by a | indicate "or," quotation marks indicate exact text must match, and parentheses specify that one of the set of terms within the parentheses must appear in addition to the term outside. The following specific searches were conducted:

   ("early intervention" | "early psychosis" | "coordinated specialty care") transition
   ("early intervention" | "early psychosis" | "coordinated specialty care") discharge
   ("early intervention" | "early psychosis" | "coordinated specialty care") (step-down | "step down")
   ("early intervention" | "early psychosis" | "coordinated specialty care") (step-up | "step up")
   ("early intervention" | "early psychosis" | "coordinated specialty care") graduation
   ("early intervention" | "early psychosis" | "coordinated specialty care") guideline
   ("early intervention" | "early psychosis" | "coordinated specialty care") "continuity of care"

   In addition, ad hoc searches were conducted as new terms and concepts emerged, and to identify specific areas, for example, alumni programs, telehealth, etc.

2. Using a list generated by Advisory Panel members, we initially targeted approximately 15 websites for review (see Appendix A). For each website, we explored the different sections, looking primarily at areas such as "Resources," "Training," "Technical Assistance," or "Publications." We particularly tried to identify any relevant reports, issue briefs, guidance documents, training manuals, standards, etc. If the site had a search function, we did a search for key words and sorted through the results.

3. We solicited suggestions and recommendations for unpublished reports, presentations and sources from our Advisory Panel members and other individuals involved in the project.

C. Existing Data

SAMHSA, ASPE and NIMH funded an evaluation of CSC programs from 2016-2019, called the MHBG 10 Percent Set-Aside Study. This study included site visits and in-depth interviews with 36 CSC programs located across the United States (Westat, 2019). The study incorporated several questions about transitions that are relevant to the current study. Some of these were incorporated into the Final Evaluation Report, as well as included in a publication (Jones et al., 2020). For the current scan, we have analyzed MHBG data to align with the current research questions.

D. New Data Collection

1. NRI, a research organization affiliated with NASMHPD, works with state agencies, the Federal Government, and other entities to define, collect, and analyze data on public behavioral health systems. In August 2019, NRI administered a survey to all SMHAs, specifically focused on transitions. This survey included several items that overlap with our research questions (see Appendix B). In total, responses from 47 states are included in this summary. Within the responses, some SMHAs provided information about individual programs within their state.

2. As part of a needs assessment conducted for the American Psychiatric Association, NRI administered a survey to all current CSC programs covering a range of topics. NRI included three questions with direct relevance to the CSC Transitions Study (see Appendix B). Data collection is ongoing; in this report, we incorporate data from responses provided by 50 programs that had either partial or completed surveys as of March 1, 2020.[2]

[2] At the time of this report, the survey data collection was incomplete, and active follow-up was discontinued after the increase of COVID-19 activity in the United States.

III. FINDINGS

A. Terminology

Clinicians and researchers in the field of early intervention use a mixture of terms to refer to services designed to address ongoing needs of individuals enrolled in CSC programs. Within the broader field of health care, **continuity of care** is the concept that services received over time should be cohesive and connected (e.g., Bachrach, 1981; Haggerty et al., 2003; Sparbel & Anderson, 2000; Holland & Harris, 2007). The term often appears in the context of describing services for individuals with psychosis who are hospitalized (e.g., Puntis, Rugkåsa, & Burns, 2016; Holmes et al., 2005). It is less frequently used in studies that track clients as they move from early intervention to other services, although the term continuity of care appears within the NIMH guidance on CSC services (Heinssen et al., 2014) as well as in the title of the solicitation for the current study.

One of the most often cited efforts to define and frame continuity of care is a typology drawn from across the fields of mental health, nursing, primary care, and disease management (Haggerty et al., 2003; see sidebar on the following page). Ahmed (2015) drew from Haggerty's framework to examine stability of the *initial* discharge placement for the three years following an early intervention program. He found that most clients (between 78 percent and 93 percent, depending on the nature of the initial placement) were able to maintain either relational or management continuity across time. While continuity of care is often referenced as an important consideration in planning quality early intervention services (e.g., Azrin, Goldstein & Heinssen, 2015; Rosenblatt & Goldman, 2019), the work by Ahmed demonstrates that a relatively simple framework offers one way for clinicians and researchers to discuss continuity of care in more concrete terms.

Three types of Continuity of Care
Haggerty et al. (2003)

Informational continuity
The use of information on past events and personal circumstances to make current care appropriate for each individual.

Management continuity
A consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs.

Relational continuity
An ongoing therapeutic relationship between a patient and 1 or more providers.

Drawing on the work of Haggerty, as well as others, Vandyk et al. (2013) used existing continuity of care measures to identify nine domains consisting of 23 separate

elements. While generally (although not exclusively) intended to reflect care received within a system, these domains and elements are also relevant to processes and practices provided for individuals attending a CSC program and discussions of what services should follow. Several of the elements identified map to the recommendations for transition planning offered in the EIP guidance (e.g., Jones, 2016; Pollard & Hoge, 2018), such as providing services that are tailored to each person and involve active collaboration with the client, clear documentation of information and transferring information across settings, and fostering a sense of mutual responsibility between providers.

Transition planning as described above is a planned process undertaken with enough time to provide at least some continuity; however, a high percentage of FEP clients drop out, disengage, or leave before clinically recommended. Definitions of **disengagement** vary, for example, by how long a client must be out of contact to be considered "dropped out," whether the termination is due to clinic policy or actively initiated by the client, and whether the treatment team agrees with the decision. As one example, OnTrackNY documents the reason for discharge and differentiates between whether the team felt that services were still indicated or not, and whether the team was able to ensure that appropriate mental health services and community supports were in place or not. Disengagement is a significant issue; across various methods of documentation, a 2014 review found rates of disengagement between 20.5 percent and 50 percent (Doyle et al., 2014) and a recent analysis of OnTrackNY data reported the probability of a client being discharged before one year was 32 percent (Mascayano et al., under review). While a critical issue, the current review focuses on transitions that occur following completion of a program (i.e., situations in which the team determined that services were no longer needed or they were terminated as a result of clinic policy).

The term **discharge** connotes a formal process after which clients are no longer served in the same manner as before. Ubiquitous in the medical field and especially to describe leaving a hospital, researchers also use discharge to describe the exit from early intervention (e.g., Cotton et al., 2017; Robinson et al., 2010; Dodgson et al., 2012; Puntis, Oke & Lennox, 2018; Ahmed et al., 2019). Some programs have borrowed and even embraced this term; most notably, the Orygen YouthHealth Clinical Program in Australia offers a handbook for clients of their program entitled, "A guide to all the ins and outs you need to know about discharge from Orygen," adding that "*discharged* is the word we use to indicate that a young person has finished their treatment with the service".[3]

With increasing frequency in both research and practice, the term **step-down** is being used in FEP programs to denote a move to services at a lower level of intensity or frequency. Notably, the NIMH description of core components of the CSC model (Heinssen, Goldstein & Azrin, 2014) identifies the fifth component of CSC to be "transition to step-down services with the CSC team or discharge to regular care after 2-3 years, depending on the client's level of symptomatic and functional recovery." Of

[3] See https://oyh.org.au/sites/oyh.org.au/files/OYH%20Discharge%20guide.pdf.

course, the specifics of this stepped-down care vary from program to program, and are just emerging in the United States, as the current project is designed to highlight.

Early intervention programs outside the United States, which have generally been in place longer, provide some specification of what step-down services might entail. For example, clients in the Early Assessment Service for Young People with Early Psychosis program in Hong Kong receive services in a transitional step-down clinic during the third year of their treatment, where they are served in the same clinic and with the same psychiatrist as during the early intervention program, but with a focus mainly on crisis intervention (Ho et al., 2018; Chang et al., 2017). Clients who receive step-down services through Ontario-based Prevention and Early Intervention Program for Psychoses (PEPP) continue to see the same psychiatrist and case manager with the focus shifted to adherence, employment and education, understanding of the illness, reducing dependence on services, relapse prevention, promoting independence, and providing crisis intervention if necessary (Norman et al., 2011). In Australia, one major clinic defines their step-down services as a client seeing the same case manager as while in the early intervention program, but receiving services within the broader agency (Murphy et al., 2009). In sum, "step-down" services have generally come to mean a reduction in the frequency of services, the type (number of different) services, or a combination of these two. The same or different providers may provide step-down services, and within the same or in a different setting. We recognize the growing use of this term but also acknowledge that it is incomplete, since at least some percent of CSC participants require a "step-up" following a program.

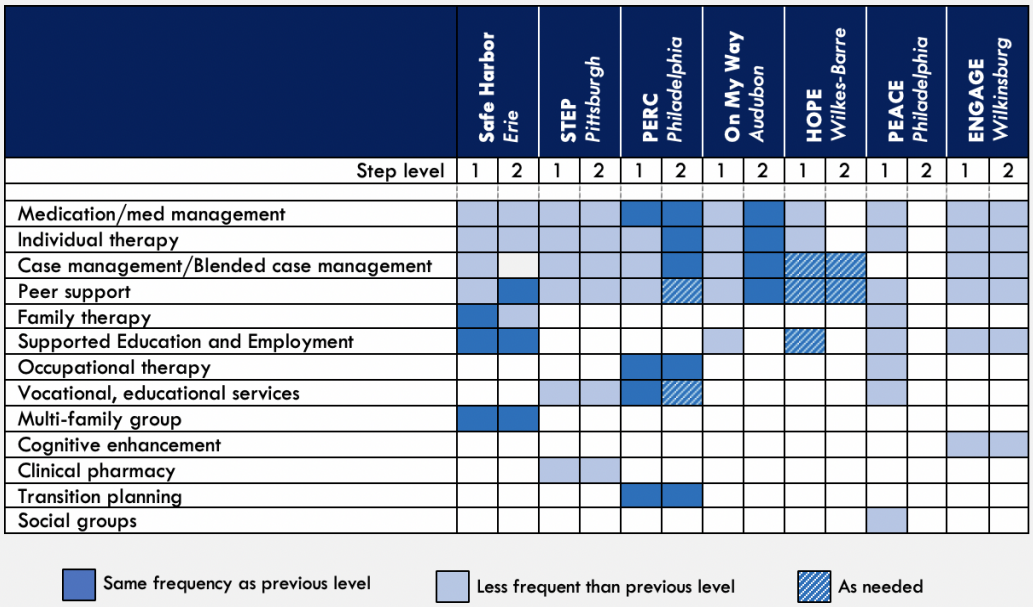
When We Say "Step-down," What Do We Mean?

1. **Reduction in intensity** of services received, which could be achieved through:
   - Reduction in the number/type of services received (e.g., no longer receiving SEE).
   - Reduction in the frequency of services/contact with staff (e.g., moving from weekly to bi-weekly).
   - Reduction in both number/type as well as frequency of services.
   - Change in modality of services (e.g., changing from in-person to teletherapy).

2. A **shift in focus**, which may include increased emphasis on:
   - Medication maintenance.
   - Overall relapse prevention and continued maintenance of wellness.
   - Goals related to functioning and stable relationships.

Services may be provided by either the **same or different staff**.
Step-down services generally take place **within the same setting** but may involve an outpatient program or different clinic than the FEP program.

Exhibit III-1. Step-Down Pilot Projects in Pennsylvania



Data source: Hurford (2019).

Pennsylvania Step-Down Pilot Study

In Pennsylvania, a pilot study is exploring different approaches to step-down services through a pilot study (Hurford, 2019). Seven first episode programs are participating, representing different types of settings and agencies. All programs begin with the full CSC model and clients receive services a minimum of every 2 weeks. As shown in Exhibit III-1, the programs then vary with respect to how a change in intensity occurs (e.g., whether through a reduction in frequency than before [indicated by light blue shading] or discontinuation of a specific service [indicated by white]). For example, in the first step after full CSC, the Safe Harbor program in Erie reduces the frequency of visits for medication management, individual therapy, case management and peer support, but maintains the same frequency for family therapy, SEE and multi-family groups. In the next step, there is a further reduction in frequency for medication and individual therapy, and case management is no longer provided. In contrast, PEACE in Philadelphia reduces the frequency of all services and does not have a subsequent step before discharge.

What is noteworthy about the Pennsylvania pilot is that clinics are approaching the process of step-down services systematically, with prescribed processes for when a service is reduced or discontinued. With programs located in diverse settings, it may ultimately be difficult to compare outcomes from 1 site to another, but data from the processes alone are likely to provide instructive information to programs contemplating step-down services. Did clinicians find the specifications of frequency useful, and realistic? Did guidelines generally fit with client needs and desires, or were further modifications needed (i.e., Was the trajectory for each client ultimately individualized? Were there any subgroups of clients for whom these steps did not seem to work? How would clinicians suggest the steps be improved?). Addressing these, and other related questions, will be able to help shape step-down models elsewhere in the United States.

B. Current Models for Post-CSC Services

A central goal of the Coordinated Specialty Care Transitions Study is to identify current approaches used within the United States to provide services to individuals following treatment in a CSC program. In this section we present an overall schema to describe overall approaches, followed by more detail about different aspects, including settings and level of services following an early intervention program and program length.

Overall Approaches to Services and Transitions

Our review of approximately 50 programs suggests that the trajectories of clients attending a CSC program vary based on three main factors: (1) duration of the CSC program; (2) the nature of step-down/transitional services available (i.e., none, a separate step-down program, or step-down/transitional practices that occur as part of the CSC program); and (3) whether the placement following the transition is within the broader community or the same agency that provided the CSC services. In each of these patterns, the services following a CSC program may be either of lower *or* higher intensity than the program. Drawing across all our sources of data, we represent the overall patterns currently seen across CSC programs in Exhibit III-2.

Pattern A is one in which a client receives focused CSC services for approximately two years (though sometimes longer), followed by a referral for services either within the same agency or outside the agency. Clients receive assistance in making a transition, such as through a warm hand-off where the clinician might accompany the client to a session or otherwise help establish a new connection; discussion of relapse prevention; and other preparatory strategies.

Pattern B reflects programs that have developed or defined a program that is separate from their CSC services, and which is considered a step-down in some respect. The services received in the step-down program can be either a reduction in frequency or intensity, or they can also be a different set of services, and often last 1-2 years. After participating in the step-down program, clients are discharged and receive services either in the same agency or within the community.

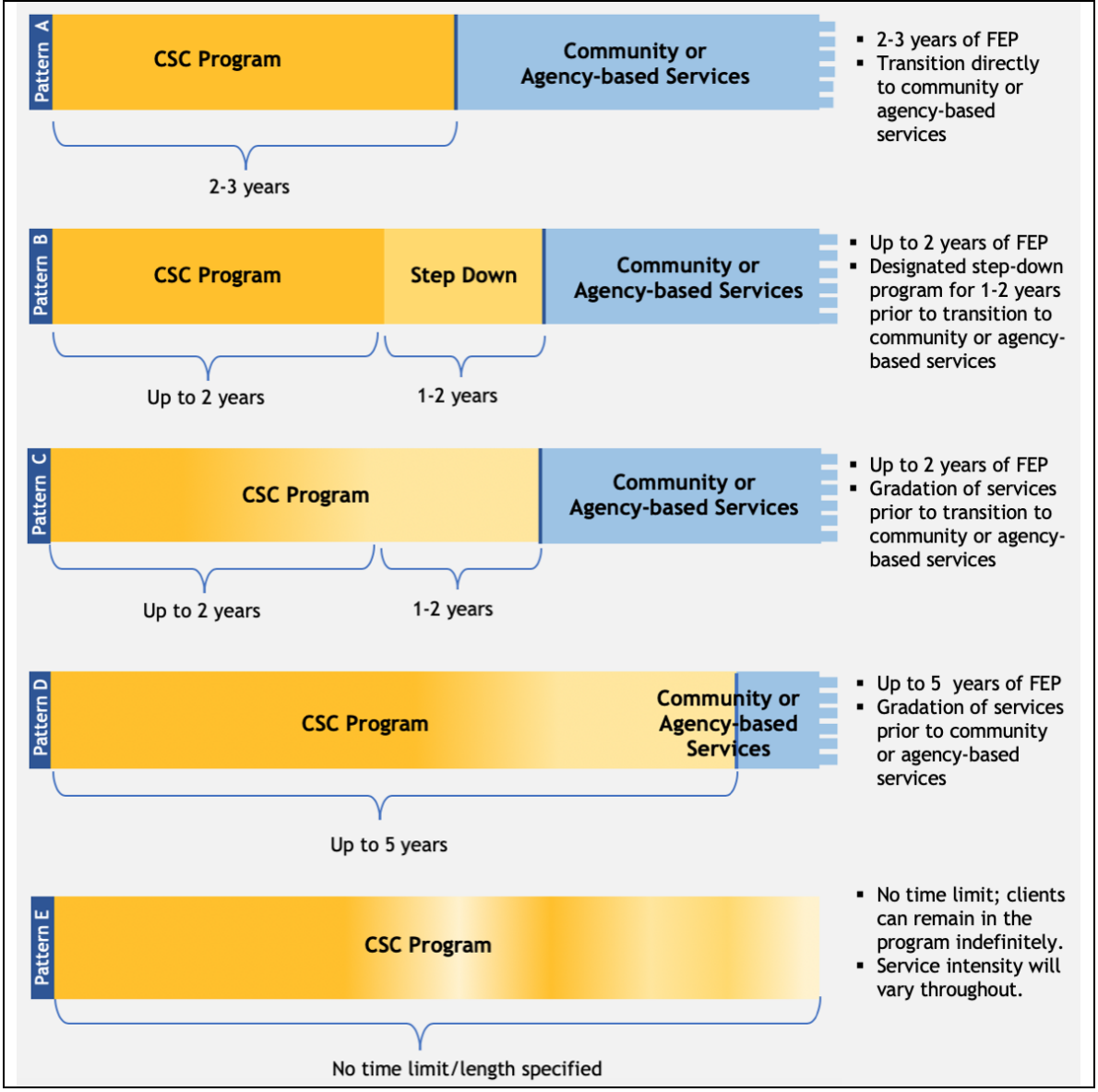
Pattern C contrasts with B in that step-down services are incorporated into the CSC program, which is approximately 2-3 years in length. Clients may receive services less frequently or may receive fewer services overall, for example, shifting from therapy, medication management, supported employment, and case management to just medication management and case management. After a transitional period, clients are formally discharged from the CSC program and receive services either in the same agency or at some other location in the community.

Pattern D describes a set of programs in which participation in the CSC program is longer, most typically stated as five years. With services spread out over a longer time, there are periods where clients may have limited contact with the program and may come back if needed within that window. In other programs, there may be a natural

decrease of services with an eventual transition to services either at the same agency or in the community.

Pattern E reflects programs in which clients can remain indefinitely. The intensity of services within the CSC program will vary according to the clients' needs, but there is no stated maximum time that a client can be enrolled.

Exhibit III-2. Patterns of Service and Transitions



Within these general patterns there are still additional variations; for example, the degree to which a program is flexible about its duration of services (e.g., allowing a client to stay an extra month vs. an extra year); at what point within the CSC services that a step-down approach is taken (e.g., within the first six months, only six months before the anticipated graduation); or whether a client can increase the intensity or frequency of services even after "stepping down." The patterns described above

represent general approaches to serving clients, but an important note is that the trajectory for a particular client may still vary. For example, a program may incorporate step-down services as an approach, but a client who continues to experience more challenges may be transitioned to services of higher intensity than the CSC program itself.

Exhibit III-3. Patterns of Transitions Among CSC Programs

Pattern	Number of Programs	%
Pattern A	25	46.3
Pattern B	8	14.8
Pattern C	9	16.7
Pattern D	7	12.9
Pattern E	5	9.2
Total	54	100

Data source: NRI/NASMHPD State Mental Health Authority Survey, NRI/NASMHPD CSC Program Survey, and MHBG 10 Percent Set-Aside Study.

In Exhibit III-3, we provide a summary of the number of programs that fit in each of these general patterns. Among programs with descriptions available to us, the most common trajectory for clients was for clients to attend a CSC program for 2-3 years, followed by transition to either services within the same agency or within the community, appearing in Exhibit III-2 as Pattern A.

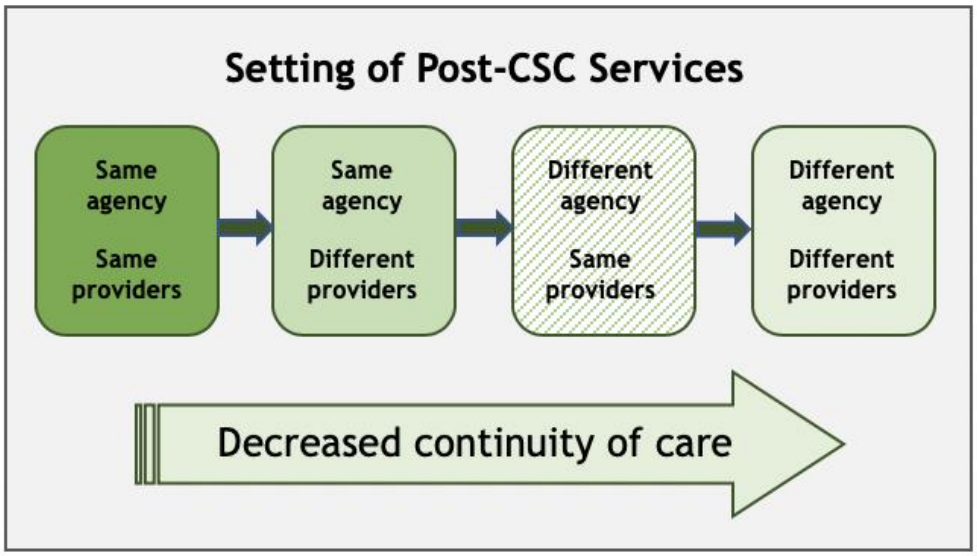
Pattern E merits note because it contrasts with the general concept of an intensive, time-limited program and the recommendation to "consider all CSC services transitional" (Pollard & Hoge, 2018). A minority of programs exhibit Pattern E, and some of these classified as such in Exhibit III-2 may not actually keep clients any longer than other programs in practice. Irrespective of whether these programs should be considered CSC or not, they do reflect a model of treatment that is being provided for individuals experiencing first episode psychosis.

Given that our combined sources reflect perhaps just 20 percent of CSC programs in the United States, we caution that these data should not be used to generalize about programs nationally. In addition, there may be both errors in interpretation of practices, as reported by the sites, and for MHBG study sites, changes in practices that have taken place since the time that data were collected. Future surveys of CSC programs could incorporate a question about this area to obtain a systematic assessment of trajectories.

Settings and Services Following Early Intervention

As originally conceptualized, CSC programs are intended to lead to a transfer or discharge at some point in the trajectory of a client's treatment, followed by community or agency-based care as needed. At the broadest level, clients can either continue in the same agency or be referred to a different agency/setting, and can be seen by either the same or different providers, in some cases, individual practitioners in the community (or a combination of these). Continuing with the same providers within the same agency clearly affords the greatest continuity of care (see Exhibit III-4). For example, in one agency in the MHBG sample, the CSC case managers and therapists work half time in the CSC program and half time in the outpatient clinic.

Exhibit III-4. Post-Discharge Placement and Continuity of Care



A transfer within the agency, albeit with different providers, will at least allow a client a familiar environment and the possibility for some type of informal communication between CSC providers and new clinicians. While rare, we know of at least one CSC program where a transition results in a different agency but consistency in a provider: the program is housed in a child-serving agency, and the SEE specialist on the team works at the adult mental health agency in the same community, which is the primary location to which clients are transitioned after completing the CSC program. Transitioning to different providers in a different setting offers the least continuity of care, and greatest risk that clients may not continue with services. For example, as one CSC team explained, it is "much more complex to coordinate" when looking for comparable Clozapine services in the community, since Clozapine has serious side effects and requires regular blood tests. A CSC team member said it is also hard to "trust that they're being discharged to a program that will provide care in the same framework" when referring to another outpatient clinic. Team members noted that transfers to outside providers often resulted in a client getting "lost" by either never meeting the new provider or quickly dropping services.

In the United States, what is the most common "next" setting where young adults are served, what services are received, and who provides these? Based on sites included in the current scan, somewhere between **40 percent to 60 percent** of programs can serve CSC clients within their own agency following completion of the CSC program. From the MHBG data, we know that at least six of the 16 sites that provide within-agency referrals are also able to serve at least some of their clients with one or more of the same providers as they saw while in the program, most frequently, the prescriber. Exhibit III-5 provides data from both the MHBG and the NRI/NASMHPD CSC Needs Assessment Survey.

Exhibit III-5. Placements After Discharge Among CSC Programs in the U.S.

MHBG study sites (N=36)

- **16 programs** (44%) "typically" referred clients to programs within their own agency.
- In **6 of 36 programs**, clients were able to remain with at least one of the same providers they had while in the CSC program.

NRI/NASMHPD CSC Needs Assessment Survey (N=38)

- **22 programs** (58%) refer to their own agency.
- **4 programs** (11%) transition to community-based services.

An International Perspective on Variability in Placement

By looking at discharge placement data from studies only within a single country--the U.K.--it is evident how much the location of services can vary following early intervention programs. In the U.K., a "primary care setting" is one in which a general practitioner provides the care. In some cases, this could include support from an initiative called Improving Access to Psychological Therapies (IAPT), which is designed to provide mental health care within the primary care setting (Clark, 2011). However, IAPT is not at all similar to CSC services, nor does it exist in all primary care settings. As shown below, the percent of clients who were discharged to a primary care setting across 4 studies published between 2013-2018 ranged from 27% to 84%.

	Percent Discharge to Primary Care
Kam et al. (2013) *N=182*	27%
Harrington et al. (2013) *N=119*	42%
Puntis et al. (2018) *N=701*	84%
Ahmed et al. (2018) *N=508*	47%

Level of Services Following Early Intervention

With CSC programs generally adopting a recovery orientation, most discussion is about moving from the CSC program to less intensive services. However, there are circumstances where this may not be clinically appropriate. If a client has been actively participating in a CSC program and has not made measurable progress, a CSC team is likely to discuss whether different services are needed. One CSC program noted that if they have worked with a client for about a year without seeing much progress, they will explore a transfer to a different setting, and in particular, have had success when clients have moved to a Dialectical Behavioral Therapy (DBT) skills group. There are also a percentage of clients who, in spite of even two or more years of a CSC program, will still require a high level of care. More data are needed to understand the extent to which

this occurs in the United States. In the United Kingdom, the need to transition to more intense services seems to be a minority of cases, with one study finding this to be true for about 4 percent of clients (Ahmed, 2015), whereas data from one United States study found that approximately 70 percent of clients left CSC without meeting treatment goals and roughly 45 percent of clients required a higher level of care (Jones et al., 2019).

Across our sources of data, Assertive Community Treatment (ACT) programs were the placement option most frequently mentioned for clients who need a higher level of services. ACT was generally viewed as a less ideal placement, noted to "feel like the opposite of recovery" and "a step in the wrong direction." ACT was described as acceptable for the "most needy" but generally not flexible enough for former CSC clients, since its primary focus is on keeping people out of institutions rather than helping people with employment and education as well as other domains of community participation. The use of ACT programs in the context of serving FEP clients is discussed further in Section III-E. Other options for higher levels of services mentioned through survey responses include a referral to Community Support Services, which is the Medicaid program for adult consumers with serious persistent mental health diagnoses in Hawaii, and to the state Continuous Treatment Team (CTT) program in Tennessee.[4]

Program Length

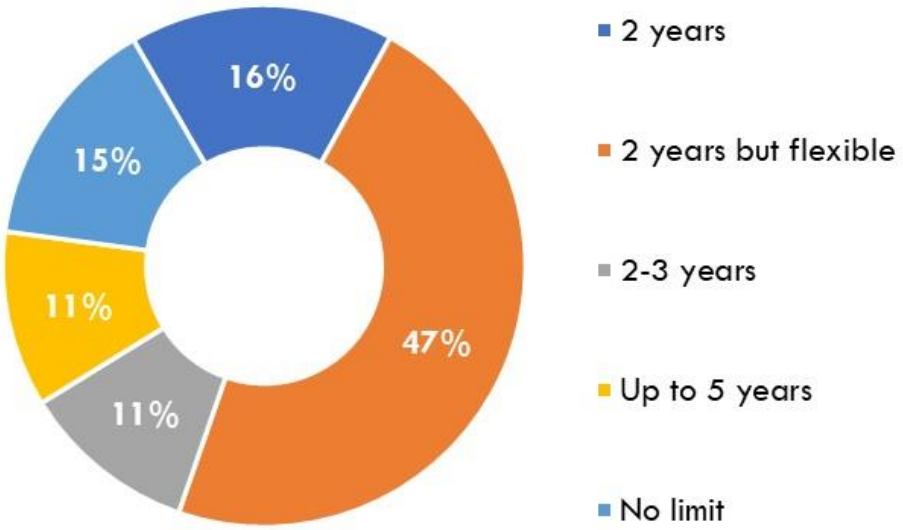
Program length is linked to service options for clients after attending a CSC program in several respects. First, a program with a clearly defined length is obligated to begin addressing post-discharge options with enough time to successfully support the client in their transition. The shorter this period, the earlier and more active these transition discussions must be. On the other hand, if a program does not have a defined length, there is less pressure to identify post-CSC options and in the minority of programs that fit Pattern E, services may continue indefinitely. Second, longer programs provide clients more time to solidify gains. Especially if services are tapered toward the end of a longer period of treatment, a lower level of post-discharge services may be sufficient and the transition to a new provider may not be as disruptive. Apart from the implications for transitions, there are competing philosophical differences in whether or not to have a time-limited program, which echo debates that have taken place for more than 20 years about whether ACT should be time-limited (Salyers et al., 1998). CSC services without limits may cultivate over-reliance on the program among clients and their families (Adams, 2019), while on the other hand, presenting CSC services as transitional and time-limited can emphasize a message of recovery.

[4] CTTs are active in the State of Tennessee, distinct from ACT teams. They serve adults, adolescents and children within families and operate through multi-disciplinary teams that provide a range of intensive, integrated mental health case management, treatment, and rehabilitation services. See http://www.valueoptions.com/providers/Network/TennCare/CTT.pdf.

The biggest challenge we have is if we discharge people at the arbitrary kind of two year mark, the gains in five years are completely gone as if our program never existed in their life and so that's really scary for us. -CSC Program Team Lead

Over the past 15 years, various organizations have weighed in on the question of optimal program length. The 2005 Consensus Statement on early intervention and recovery for young people with early psychosis, written on behalf of the World Health Organization and International Early Psychosis Association (Bertolote & McGorry, 2005) did not explicitly identify a length of optimal time for treatment, however, the statement identifies **five-year outcomes** that a comprehensive and effective program would deliver to people with early psychosis and their families. While the outcomes are identified as five year goals, measurement is specified as two years after diagnosis, for example, "two years after diagnosis 90 percent of affected individuals have employment/education rates similar to their age/gender-matched peers" and "two years after diagnosis 90 percent of affected individuals will report satisfaction with their employment, educational report satisfaction with their employment, educational and social attainments." The U.K. National Institute for Health and Care Excellence (NICE) guidelines recommend that providers offer services for **up to three years** and "consider extending the availability of EIP services beyond three years if the person has not made a stable recovery from psychosis or schizophrenia" (NICE, 2019).

Exhibit III-6. Program Length



Data source: NRI/NASMHPD State Mental Health Authority Survey.

In the United States, the RAISE-ETP study provided treatment for "a ***minimum* of two years**" (emphasis added), and participants who enrolled early could receive treatment up to 43 months. NIMH guidance following RAISE-ETP (Heinssen, Goldstein & Azrin, 2014) noted that CSC services should be offered over a "**two-three year period** following psychosis onset" and added that continuity of care "**up to five years**" may be important to maintain progress made while in the program. All of these stem from the

critical period hypothesis, that the early years of psychosis offer the best opportunity for successful treatment (Birchwood, Todd & Jackson, 1998).

Based on data from the MHBG and the NRI State Director Survey, the most common program length among CSC programs currently is two years with flexibility to extend, depending on the clients' needs. Among the 55 programs with available information about program length, approximately 47 percent described their program length as two years but with the understanding that a client may stay longer (see Exhibit III-6). However, whether individual programs can determine the program length and the degree of flexibility in extending the program length by client varies by state. Based on the NRI Survey of State Mental Health Authorities, five states have a "hard" limit of 24 months. Examples of flexibility in program length among programs appear in Exhibit III-7.

Exhibit III-7. Examples of Flexibility in Program Length as Reported by Programs from States

- Usually the program is time-limited for early psychosis, typically it is a 2 year program, barring any changes.
- As far as just a usual time frame, it is up to 2 years.
- The program is between 6 months and approximately 2 years.
- 2 years is recommended, but we recognize there are a variety of reasons where extending would be appropriate.
- The goal is to have a participant ready and feeling supported in their transition at 24 months. If they are not ready at 24 months, then programs will flex to allow for warm hand-offs and participant readiness. The flex does not usually go for longer than an added 2-3 months.
- It aims to provide services for 2 years. However, the program is flexible and will keep participants for longer if they are not yet ready to transition or are in crisis.
- We do have clients that require a little over 2 years of treatment for appropriate transition; when this occurs, we continue to provide them with CSC services.
- 24 months but we have built into the requirements a process to request an extension based on individualized need as clinically determined and approved by the state.

Data source: NRI/NASMHPD State Mental Health Authority Survey and MHBG 10 Percent Set-Aside Study.

C. How CSC Programs Prepare for Transitions

Determining Readiness

To assist with determining whether a client is ready to transition to another level of care or service, several CSC models offer a checklist or "talking points" to guide the process. The **OnTrack** model uses a CTI approach, which is significant because it is a model with a relatively fixed period of intensive services before transfer to community services (Susser et al., 1997), (i.e., the notion of a time-limited treatment is central to the model), unlike some other approaches. Phase 3 of the model used by OnTrack focuses on preparing for and facilitating termination and services to follow. This phase can occur any time after a client has been in the program for a year, and the model has a session dedicated to initiating this discussion. OnTrack has developed a Transition Planning

Tool to help determine whether treatment goals have been met and the client is ready to discharge. This process incorporates input from all the team members as well as the client and his/her family. The tool itself has three components: (1) Progress that the client has made during the program in each of five domains, and the client's vision of success in the community; (2) What support might be needed in each domain to support the vision of success; and (3) What practical issues might need to be addressed. The transition worksheet includes tasks to be completed by both team members as well as the client/family. Several CSC programs that follow OnTrack commented on the usefulness of this structure, such as a program director who noted that they find that beginning the document 2-3 months prior to actual transition during one-on-one sessions with the client is useful, as well as having felt they were able to greatly help clients through a final meeting where the client, family, and team all review the document together.

Transition planning prior to a discharge is also an explicit aspect of the **EASA** model, which emphasizes that the program is time-limited from the start of services. EASA has developed a tool to facilitate transitions, which is initiated six months before anticipated program completion. The tool/form has seven sections with a series of questions in each, as well as a place for additional information to be written, for example, if the response to the question, "Is there a current crisis/safety plan" is "no," then, "Who is going to create/update one?" While structured as a set of yes/no items, there is not explicit guidance that a certain number of "yes" items suggests that a person is ready; the checklist is intended more as a guide.

The BeST Center has developed "talking points" to guide transitions from programs that follow the **FIRST** model. These are six questions that are used as a client expresses a desire to transition to a lower level of care. The general areas covered in these questions have commonalities with the OnTrack tool, for example, assessing progress in a set of domains and asking whether the client can identify individuals who will provide support once the client is no longer enrolled.

Pollard and Hoge (2018) provide a list of 12 factors to consider in determining readiness for a transition. In Exhibit III-8, we have categorized these into: (1) client progress in treatment; (2) client functioning and stability; and (3) external support. Using survey responses and the MHBG study data, we then provide specific examples that align with these 12 factors.

One factor Pollard and Hoge allude to is client perceptions. A study in the United Kingdom involved interviews with 21 individuals approximately three years after they had left an early intervention program (Lester et al., 2012). Drawing across responses from these former clients, Lester concluded that "ensuring the service user themselves felt ready to move on and recognized their ability to self-manage seemed particularly important" as a factor in determining when to transition (Lester et al., 2012, e186). This is consistent with responses from the current analyses, in which CSC programs frequently mentioned that a critical indicator is when the client feels they don't need to come or indicates that they feel ready to move on. The opposite can also be true: One

CSC program team member provided the following example of how taking a client-centered approach can result in a different outcome than clinical and functional indicators would suggest:

> We had one participant, he was doing great. He had been doing great for a year. He was studying, he was doing his Bachelor's, good grades. And we talked to him and said, "We think you're ready." And he said, "Oh no. No, no, no. No, no, no. Not yet. I don't want to graduate." And he stayed. He just finished. He graduated right now, but he just wanted more support…so, discharge is more patient centered.

Exhibit III-8. Factors to Consider in Transitioning

Pollard & Hoge (2018) Category	Examples from Current Programs
Treatment Progress	
Progress toward treatment goals	▪ Has achieved one-on-one therapy goals ▪ Completes the remaining sessions for discharge ▪ Have worked through the modules of individual resiliency training ▪ Met other treatment goals ▪ Active participation in treatment ▪ Have achieved the goals they set for themselves ▪ Have met their goals
Response to decreased CSC services	▪ Clinically ready for reduction in services ▪ Utilizing fewer services ▪ Decrease in frequency of visits ▪ Using fewer than 2 services
Ability to manage symptoms	▪ Have identified recovery goals with continued progress ▪ Have a commitment to continuing treatment ▪ Are they taking care of themselves to prevent relapse ▪ Managing symptoms ▪ Developed a safety plan and practice coping skills ▪ Have the skills to maintain the achievement of these goals
Medication adherence	▪ Seeing the doctor regularly for medication management ▪ Stable on medication for at least a period of time
Functioning & Stability	
Clinical stability	▪ Reductions in symptoms ▪ Chronic residual symptoms or remission <6 months ▪ Not currently suicidal/homicidal ▪ How long since their last episode ▪ Clinical stability for at least 6 months ▪ No inpatient hospitalization within the 2 months prior ▪ Have not been in the hospital for a year
Level of functioning	▪ Secured/are interested in securing employment or continuing education ▪ Improved functioning in daily living, academics/employment ▪ Sustaining life goals in terms of education, work and relationships ▪ Managing life effectively; ideally employed or in school ▪ Working steadily or going to school for a period of time ▪ Optimal functioning
Ability to engage	▪ Social engagement
Physical health	▪ Are in a place of wellness
Developmental stage	*No examples located*
Substance use	*No examples located*
External Support	
Support system	Independently uses family and community supports Family functioning and support system
Stability of the housing situation	*No examples located*
Data source: NRI/NASMHPD State Mental Health Authority Survey and MHBG 10 Percent Set-Aside Study.	

Facilitative Practices

A transition from any system or program to another will always entail some degree of disruption. With the exception of the small number of CSC programs from which clients never have to leave (i.e., Pattern E described above), every other pattern of transition will involve an interruption of some type. Lester (2012) described "good" transitions as planned and expected, with a high level of personalization to facilitate flexibility in the process. In the study described above, Lester identified six themes regarding effective transitions from the perspective of the client: (1) Ensuring that the client feels ready to move on; (2) The client is involved in the planning; (3) The transition is planned and expected; (4) There is a strong sense of personalization of the process; (5) There is flexibility regarding the timing of the discharge; and (6) There is good communication between the current and future providers. These six have some commonalities with those viewed by current CSC programs as especially effective approaches. Exhibit III-9 presents a sample of responses to the question, "Do you have any practices related to transitions or continued care of services that you feel have been particularly effective or beneficial for clients?"

Exhibit III-9. Examples of Common "Best Practices" to Facilitate Transitions

Establishing Connections with Receiving Providers

- We identify the person that the client will be transitioning to and bring them into treatment meetings for "warm hand-off's" prior to the client leaving our program.
- Outreach to local community agencies, we have 2 outpatient clinics that we refer graduates of the program to. It is important to develop step-down programs.
- Warm transfers to continued care and ensuring clients are linked to necessary resources.
- We have learned that to get participants to engage effectively with multiple team members, we have to do warm hand-offs both within the team as well as to any external providers. This usually means 1 or more co-visits with the primary staff member and other team members. Even when a client was requesting an additional service within the team, it often did not work to simply schedule an appointment with the other staff member. This would usually be followed by multiple missed appointments. Co-visiting reduced this greatly.
- We have utilized a transition process that requires the lead provider from the children services and adult services to work together for a least a period of 6 month as part of the warm hand-off process.
- Developing provider networks to refer step-down clients.
- We link clients transitioning out of the CSC program, to providers that are appropriate. In doing this, we attend the first few appointments with the client if they wish to provide a "warm hand-off".
- We transition to the provider of choice and prepare the client months in advance and, with the client's permission, schedule an appointment to accompany them to their first appointment to their provider of choice to make the transition as smooth as possible.

Continued Contact with Clients

- When an individual is transitioned to step-down services within the agency the case manager will continue to monitor until complete transition is completed.
- Upon departure from our program we do allow for follow-up between the client and an identified program employee (peer, therapist, IPS, etc). We do not want anyone getting "lost in the cracks" once they leave our program.
- We have a monthly drop in group for alumni to connect or problem-solve together. Patients remain with our psychiatrists when they transition out of the program, so they remain connected that way, too. And we also have an "open door policy" so people can return after graduation if they need additional assistance later on getting connected with services.
- Applying engagement strategies and individualized care while monitoring appointment adherence.
- We keep the person enrolled while shifting resources all the way through being connected afterwards, and check in even after discharge.

Data source: NRI/NASMHPD CSC Needs Assessment Survey.

The two general strategies that programs most frequently noted were **establishing connections with the receiving provider and continuing to maintain contact with the client** even after discharge. The former of these receives an extensive commentary in the guidance by Pollard and Hoge (2018), in which the authors even offer suggestions about how to assess providers' knowledge and tactfully educate them about the nature of CSC services and first episode psychosis, as distinguished from more chronic presentations. The latter approach, of continuing contact following the transition, is more complex. While a period of overlap may be permitted, demands on providers' time may be an impediment for a clinician to schedule one session with the new provider. Structural factors also play a role. Insurance policies may not allow payment for similar services by two agencies; formal discharge may be necessary for a receiving provider to be able to bill, and an agency may not allow non-reimbursable care to a client (Pollard & Hoge, 2018). In addition, some privacy regulations may not permit continued contact with an individual who is no longer a client. Most of these challenges do not apply when a client continues to receive services within the same agency and with the same provider. Unfortunately, transitions that involve the greatest disruption to continuity of care are ones that place a client at highest risk for getting--as described by one CSC team lead--"lost in the cracks" once they leave the CSC program.

D. Challenges in Transition Practices

With many programs in the process of developing post-CSC options, known challenges associated with this process can be instructive to identify areas for potential intervention. We obtained information about challenges through three different mechanisms: (1) Responses to a multiple choice item on the NRI/NASMHPD CSC Needs Assessment Survey; (2) Responses to an open-ended question on the NRI/NASMHPD State Mental Health Authority Survey; and (3) Data extracted from MHBG interviews on the general topic of transitions. Responses from the latter two sources were coded to provide context for the survey item completed through the CSC Needs Assessment Survey.

Lack of Appropriate Services

As shown in Exhibit III-10, programs most commonly identified challenges associated with lack of appropriate services, and specifically identified the absence of providers who either specialize in or have expertise in psychosis and can provide appropriate therapy (64 percent). Respondents noted that providers themselves express concerns that they cannot offer enough care or are not adequately trained to treat someone who has experienced psychosis at some point, even if they are not psychotic at the time of transfer. Respondents also felt that access to providers who work well with individuals with treatment-resistant psychosis is limited, and there is a need for more community-based clinicians trained in CBTp and family psychoeducation. During the time that clients attend a CSC program, they are typically offered SEE services and case management in addition to therapy and medication management, and may also have access to peer support. Sixty-two percent of respondents reported that finding these

services in the community, particularly supported employment and peer services, is a challenge.

> *Sending them to local clinics or to our own clinics has been a barrier. They seem to become symptomatic and/or become re-hospitalized. We've noticed that people that we referred to our other clinics in the area or even our own clinics, we tend to get calls back from their parents saying that they are not well again.*

More generally, respondents identified a range of ways that differences in the therapeutic environment between the CSC program and either community-based services or even their own clinics was a challenge. The explanations included a number of process-oriented factors, such as lack of flexibility within service providers (e.g., quick discharge for a missed appointment, strict "no-show" policies, not being seen if the client is five minutes late and still being charged) as well as less frequent follow-up, clinicians not providing services in the home, less client and family engagement, and less ability to communicate with the treatment team. Challenges with the therapeutic environment also included providers not engaging in shared decision making, not being able to respond to fluctuations in clients' need for more intensive treatment from time to time, and not being youth and family-friendly. As one program noted, "It is very harsh for some participants to go from the comprehensive and supportive coordinated specialty care to community-based adult mental health services." Most of these factors reflect inflexibility in the mental health care system that would be frustrating for anyone seeking services, but for individuals with psychotic disorders who are coming from CSC programs, the contrast is likely to be greater and the challenges may be exacerbated.

Forty percent of survey respondents reported issues with psychiatrists and prescribers as a special type of challenge. Several program staff reported that local providers were not always educated in protocols and best practices for treating patients with first episode psychosis. A small number of respondents specifically mentioned the challenge of obtaining prescriptions for Clozapine. As noted before, this is likely due to the higher level of care and monitoring that is needed when someone is on this medication.

Insufficient Payment and Insurance

Overall, 56 percent of survey respondents identified a challenge related to payment and reimbursement for services for clients following a CSC program. With respect to clients with private insurance, the major challenge is that some companies either do not reimburse or reimburse less than the cost for needed services, such as wraparound. Copay requirements can also be difficult for many clients, especially if they need frequent contact. Some insurers also may require prior authorization for each instance of service. Respondents often identified issues with Medicaid. In Nebraska, for example, care coordination is often needed, but is not reimbursable. A respondent from Texas noted that collateral contact without the client present is not a billable service. A respondent from Kansas noted that as a result of not being a Medicaid expansion state, there can be problems with accessing services for persons who would otherwise qualify for Medicaid; a respondent from Idaho noted difficulty in obtaining psychiatric services for clients with Medicaid. One respondent noted that there were very few psychiatrists in

the area who accepted either insurance *or* Medicaid, so clients would be required to self-pay.

Exhibit III-10. Challenges Reported by CSC Programs (N=50)		
	N	**%**
Appropriate Services	**40**	**80**
Lack of providers that specialize in psychosis/have expertise in psychosis/who can provide psychosis-focused therapy	32	64
Lack of key services in usual care settings (e.g., supported education/employment services in usual care settings, peer services, assertive outreach, case management)	31	62
Differences in therapeutic environments between outpatient providers and CSC models	26	52
Lack of prescribers who are knowledgeable about best practices for prescribing for young adults living with psychosis	20	40
Reluctance of providers to accept clients with a diagnosis of psychosis	16	32
Providers unable or unwilling to provide care beyond psychopharmacology	11	22
Long wait list for providers with psychosis expertise	10	20
Payment and Insurance	**28**	**56**
Problems related to adequate service coverage for privately insured clients	23	46
Problems related to adequate service coverage for Medicaid/Medicare clients	16	32
Transportation	**28**	**56**
Client-Related Factors	**19**	**38**
Data source: NRI/NASMHPD CSC Needs Assessment Survey. Total is greater than 100 because respondents could select multiple challenges.		

Poor Transportation

Fifty-six percent of survey respondents identified challenges with clients having transportation to get to post-transition appointments. While especially true for clients in rural areas, this issue is common in many urban settings as well. One respondent noted that the program works with clients on learning how to use public transportation or the state Medicaid non-emergency services, but “still, they struggle, and will sometimes not bother with the struggle for treatment.”

Client-Related Factors

As noted above, many barriers in transitioning clients originate in the lack of attractive and effective community services as well as structural problems. Client-related factors were identified by 38 percent of survey respondents. Some CSC programs reported that clients were not always willing to transition, primarily for two very different reasons: either because they did not wish to leave (or feel ready to leave) the CSC program, or because they did not feel that post-discharge services were necessary at all (i.e., that they were done needing treatment and support). Given the highly supportive nature of CSC programs, it is not surprising that many clients would be apprehensive about a

transition, and reluctant to start over with new services and providers. For clients who do not want post-discharge services, program staff reported that they generally tried to communicate the need for ongoing services, but also had to maintain a balance by respecting client wishes. Another client-related challenge included the client lacking the supports needed for successful transition. Several programs noted that they would hesitate to transition clients that do not have adequate family or social support available to them.

Of note, there were eight survey respondents who indicated that they had not experienced any of the challenges identified above. In some cases, this is because the program has not yet had to facilitate any transfers because no clients have reached that point. However, one respondent explained that "because our CSC teams are operated by CSBs [Community Service Boards], we may have fewer challenges with transition than states where CSCs are stand-alone programs."

E. Policy Issues

State Involvement in Transition-Related Issues

As noted in Section 1, state factors can have a significant role in shaping post-CSC services both through providing guidance to CSC programs as well as by facilitating linkage to non-CSC community-based services. Georgia is an example of this (see box on following page). States also have an influence on CSC programs in general, including transition processes, as a result of *low* involvement. For example, states that do not set limits on CSC program length afford programs a high degree of latitude to make local decisions, but this can mean the absence of the kind of support noted above. Among states responding to the NRI/NASMHPD State Mental Health Authority Survey, 16 set no limits on program length, leaving this up to individual programs to decide; 20 have recommended limits; and nine states have hard limits (see Exhibit III-11).

Exhibit III-11. Involvement of States in Setting Program Length Limits (N=45)
No Set Limits (N=16) AR, AZ, CT, FL, HI, IA, IN, KS, LA, MI, MO, ND, NH, NM, OK, RI
Recommended Limits (N=20) AK, GA, ID, IL, KY, MA, ME, MN, MS, MT, NE, NJ, NY, OH, OR, PA, SD, TN, UT, WI
Hard Limits (N=9) AL, CO, MD, NV, SC, TX, VA, WA, WV
Data source: NRI/NASMHPD State Mental Health Authority Survey Notes: No response received from CA, DE, NC and WY. VT did not have any CSC programs at the time of the survey. In AZ, CT, FL, IN and NM the state allows the program to set the limits.

States also develop programs that, while not intended specifically for individuals with FEP, can serve as a good option for continued care following CSC. In Delaware, for example, clients are typically discharged to ordinary community-based services. For clients who need a higher level of care, the state runs a program funded by a Medicaid 1115 waiver, called PROMISE (Promoting Optimal Mental Health for Individuals through

Supports and Empowerment).[5] PROMISE is available to anyone over the age of 18 who has a behavioral health diagnosis and meets need-based criteria. The program serves as an umbrella for a range of services and supports (including ACT), and is guided by a person-centered philosophy, making it a good match for clients who graduate from the state's CSC program. Other states have similar programs that allow agencies to access services for their clients; examples from New York, Tennessee and Wisconsin appear in Exhibit III-12.

Case Study:
Georgia Department of Behavioral Health & Developmental Disabilities (DBHDD)

The Georgia DBHDD has consolidated first episode services within a framework called Listening, Inspiring and Guiding Healthy Transitions Early Treatment Program (LIGHT-ETP) and has 6 programs within the state. DBHDD supports a state-wide collaborative for the CSC programs, with meetings held quarterly. As an example of funding support, DBHDD provided a $100,000 grant to a state-wide behavioral health care provider to implement a program to assist youth with mental illness in gaining independence and support as they move into adulthood. To the same system, DBHDD also provided a grant of $334,000 to expand the DBHDD Early Psychosis Intervention Collaborative.

The structure of CSC programs within the state itself also factors into transitions; all the CSC programs are located within CSBs, the state's "safety net service providers." The CSBs offer most of the services provided by CSC, so most CSC participants can transition to the services they want and need within the CSB. DBHDD also provides a set of guidelines and procedures related to transitions and discharges, and has programs follow a Transition Planning Worksheet, which is adapted from OnTrack materials. DBHDD guidance includes the following regarding transitions:

For participants who have worked with the team for approximately 2 years and are completing the LIGHT-ETP program: Planning for the participant's transition from the team's care should begin at least 90 days before the participant is discharged from the team. Participants' length of treatment with the LIGHT-ETP team may be extended beyond 2 years when clinically appropriate.

Three Phases of Care Transition:

1. Transition Planning:
   - Engage participants/families in discussions regarding transition process.
   - Discuss participant's/family's experiences with LIGHT-ETP team.
   - Discuss participant's/family's hopes and concerns regarding transition.
   - Assess participant's strengths, needs, sources of support, and progress toward goals.
   - Develop plan for transition (see Transition Planning Worksheet), including clear timeline and assignment of tasks.

2. Linkages and Try-Outs
   - Discuss and explore options in the community for services and supports.
   - Identify participant's skills and areas where additional skills are needed.
   - Contact and try out community options: Involve Peer Support Specialists as appropriate.
   - Modify transition plan as necessary.

3. Transfer of Care, "Graduation," and Follow-Up
   - Gradually decrease contact between participant/family and team.
   - Participant/family meet new providers.
   - Acknowledge participant's/family's transition from the team in accordance with participant's wishes: "graduation" celebration, lunch with the team, etc.
   - Ensure participant is solidly connected to new services.
   - Finalize transfer of care.

[5] See https://www.dhss.delaware.gov/dhss/dsamh/files/promiseorientationandquiz.pdf.

Exhibit III-12. Examples of State Programs that Support Transitions		
State	**Program**	**Description**
Delaware	PROMISE	▪ 1115 Waiver program ▪ Targets individuals with behavioral health needs and functional limitations ▪ Offers a wide array of HCBS that are person-centered and recovery-oriented, such as care management, individual placement and support (IPS), peer support, transportation, psychosocial rehabilitation, nursing, community psychiatric support and treatment ▪ Provides a level of services similar to CSC programs
New York	Personalized Recovery-Oriented Services	▪ Considered to be a carved out program eligible to bill fee-for-service for individuals enrolled in Medicaid managed care ▪ Has four components: Community Rehabilitation and Support, Intensive Rehabilitation, Ongoing Rehabilitation and Support and Clinical Treatment (optional) ▪ Combined, these components include services such as wellness self-management, basic living skills, community living, financial management, relapse prevention, family psychoeducation, and integrated dual disorder treatment ▪ Level of services varies by program (e.g., whether only groups are offered), but generally similar to CSC programs
Tennessee	Tennessee Health Link	▪ Primary objective is to coordinate health care services for Medicaid recipients ▪ Providers are encouraged to ensure the best care setting for each member, offer expanded access to care, improve treatment adherence, and reduce hospital admissions. ▪ Program encourages integration of physical and behavioral health and mental health recovery ▪ Services include comprehensive care management, care coordination, referrals to social supports, member and family support, transitional care, health promotion, and population health management ▪ Provides a lower level of services than CSC programs
Wisconsin	Comprehensive Community Services	▪ Voluntary Medicaid program ▪ Recovery-focused, integrated behavioral for adults with severe mental illness and/or substance use disorders and children with severe emotional disturbance ▪ Eligibility determined through a screening process ▪ Noted to offer therapies such as equine, dance, and art therapy ▪ Provides a higher level of services than outpatient services, but not as intense as CSC

Funding Policies

As noted earlier, there are funding challenges associated with supporting post-CSC services, many of which are the same as funding core CSC services. For example, the Affordable Care Act extends parents' insurance benefits to offspring up to age 26, and a significant number of FEP individuals fall into this category (Shern et al., 2017). Private insurance typically does not reimburse for key CSC services, such as SEE and

outreach and other activities by the Team Lead that do not include face-to-face contact (Jackson et al., 2019; Smith et al., in press). Yet to facilitate a smooth transition, the CSC Team Lead or therapist may need to make phone calls and other contacts on behalf of the client. (We note that while private insurance generally does not cover CSC services, it does cover a number of services in the CSC model, such as physician visits, medication and labs. It therefore can be an important component of program funding if properly addressed). Sites that receive MHBG funds often use the Set-Aside funds to cover activities not reimbursed by private insurance (Westat, 2019). However, MHBG funds are not always adequate to meet population needs, not all CSC programs are supported through MHBG funding, and MHBG funding may only partially cover a CSC program. Approximately 28 percent of people experiencing FEP are insured by Medicaid (Jackson et al., 2019). For those with Medicaid insurance, a wider range of services may be available, depending on the state's Medicaid program, thereby making Medicaid an important policy lever to support services.

Although a federal program, Medicaid policy is enacted at the state level. The use of Medicaid waivers, such as the 1915(c) Waiver Authority, the 1915(i) State Plan Authority and Section 1115 of the Social Security Act are examples that have been discussed elsewhere (Shern et al., 2017). Recently, states have begun focusing on two other mechanisms. One of the current funding policies with the most significant potential implications for post-CSC care is through a tiered model of reimbursement, with different rates for different levels of service. An example of a three-level model currently proposed in Pennsylvania includes a top tier with a full case rate covering "regular" or full services, where team members see clients multiple times a week. The next tier, with funding at a reduced case rate, can cover clients who do not need to be seen as frequently but who need ongoing care, such as monthly visits. The last tier involves a fee-for-service structure, where reimbursement covers each visit, such as a client coming for medication checks every three months. In this model, step-down services align well with the second and third tiers of service. The Meadows Mental Health Policy Institute (MMHPI) makes a recommendation similar to this, proposing a monthly case rate for delivery of the full model plus an encounter rate for less intensive service delivery, which includes follow-up contact as clients transition to other levels of care (Jackson et al., 2019).

A second approach is a single "bundled" payment. The MMHPI report makes a strong case for this and suggests a billing code that is consistent with a bundled rate for CSC programs. The authors note that the effectiveness of CSC services derives in part from being a coordinated, flexible package of services using a team-based model and as such, reimbursement should follow the structure of the model. Very recently, Maine was able to achieve this by negotiating a cost-based, bundled payment, calculated as the total cost for the CSC program divided by individuals served (Robbins, 2019). In June 2019, the state passed a bill with bipartisan support, in which the Maine Department of Health and Human Services was directed to pursue federal funding sources and develop a bundled rate that will be honored by private insurers.[6] In Illinois, Public Act

[6] See https://legislature.maine.gov/legis/bills/bills_129th/billtexts/SP044601.asp.

100-1016, the Early Mental Health and Addictions Treatment Act was passed in August 2018 and included provisions for a Pay-for-performance payment model, another example of state progress in shaping Medicaid to better fit CSC services. However, the Maine and Illinois examples do not directly address funding for transition services.

Intersection of CSC and Other Federal, State and Local Programs

Apart from Medicaid, several other initiatives have been used to support young adults following a CSC program. We discuss four such mechanisms and provide examples from current CSC programs that have successfully linked with these initiatives.

Certified Community Behavioral Health Clinics (CCBHCs). CCBHCs were established in 2014 under the Protecting Access to Medicare Act, and represent a new approach to improve behavioral health services through comprehensive and integrated care (Breslau et al., 2017). In 2016, one-year planning grants were awarded to 24 states, followed by a two year demonstration project awarded to eight of these states in 2017: Minnesota, Missouri, New York, New Jersey, Nevada, Oklahoma, Oregon and Pennsylvania. CCBHCs must provide nine types of mental health and addiction services to vulnerable individuals (see box); certified clinics in these eight states in turn received an enhanced Medicaid payment rate based on their anticipated costs of providing services.[7] As of March 2020, there are 113 CCBHCs operating in 21 states.

CCBHC Required Services

1. Crisis mental health services.
2. Screening, assessment and diagnosis.
3. Patient-centered treatment planning.
4. Outpatient mental health and substance use services.
5. Primary care screening and monitoring.
6. Targeted case management.
7. Psychiatric rehabilitation services.
8. Peer support, counseling, and family support services.
9. Services for veterans.

Although CCBHCs were not designed specifically for FEP service users, many core elements of the CCBHC approach overlap with CSC services, in particular, an emphasis on whole-person care with strong care coordination and continual communication among providers, and consistent use of evidence-based practices. Moreover, addiction care is embedded throughout all CCBHC services, which is highly relevant for young adults with first episode psychosis, given the overlap with substance use in this population (Johnston et al., 2012). In a review of the use of Medicaid to finance CSC, the CCBHC demonstration waiver is noted as one of the most promising mechanisms for CSC services, since it permits reimbursement of all the CSC elements as well as using a prospective payment model that allows flexibility and a reimbursement rate that is based on the cost of the program (Shern et al., 2017).

[7] See https://www.thenationalcouncil.org/capitol-connector/2016/12/samhsa-announces-states-selected-ccbhc-demonstration/.

A CCBHC serving individuals with first episode psychosis, either as part of a CSC program located within the same agency or through other services, will presumably afford a greater degree of continuity of care, perhaps even allowing an individual to remain with the same providers. Based on a 2018 report to Congress on the CCBHC Demonstration Program (a total of 66 clinics), **60 percent** of CCBHCs directly provided first episode/early intervention services for psychosis.[8] While we do not have information to indicate which CCBHCs provided these services and how many were established CSC programs, we know of at least one example of the use of CCBHCs to fund post-CSC services. BestSelf in Buffalo, New York, used the CCBHC mechanism to create an extension program to CSC services that allows individuals to receive daily access to peer services, support from staff on rehabilitation and life goals such as employment and education, assistance with benefits management, housing, coordination of care, off site services, and access to psychiatry services including screening, medication evaluation, and management, among other services for individuals discharged from that OnTrackNY program.

System of Care (SOC). Since 1993, SAMHSA has provided more than 300 SOC grants and cooperative agreements to states, territories, counties, and federally recognized tribal entities through the Children's Mental Health Initiative. SOC is a framework to guide mental health and other related services for children, youth, and young adults with Serious Emotional Disturbances, and their families. The central concept is based on a coordinated and diverse network of services and supports that are family driven and youth guided, community-based, and culturally and linguistically competent (Stroul, Blau & Friedman, 2010). Many of the principles articulated in the SOC framework overlap with CSC, such as taking a strengths-based, proactive, flexible, responsive, and multi-disciplinary approach, all with a focus on addressing individual needs.

Sale et al. (2018) highlight the opportunities afforded through integration of early psychosis services within a SOC framework, and note that integration of SOC mechanisms and principles may improve responsiveness across partners that could lead to improved long-term outcomes. In the context of planning for transitions, this point is central: Given that a SOC framework emphasizes collaboration and relationships across agencies and sectors, a CSC program that operates within this framework is likely to have staff who already are connected to resources that can be pivotal during the transition process.

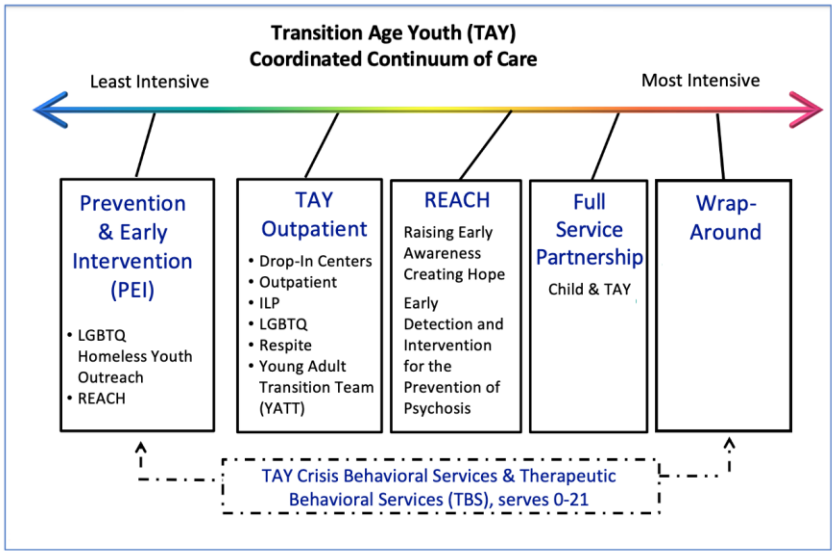
Transition Age Youth (TAY) Services. To counteract the challenges associated with maintaining continuity of services between child/adolescent and adult services (Scholz et al., 2019; Sukhera, Fisman & Davidson, 2015), many agencies implement programs specifically targeted at youth approximately aged 16-24 years old. For many TAY programs, the goal is to provide a smoother transition between children's mental health services and adult mental health services, with a particular focus on independence and issues relevant to this age, such as education, employment and housing. While not an

[8] See https://aspe.hhs.gov/system/files/pdf/262266/CCBHRptCong.pdf.

option for older CSC clients, TAY programs provide a post-discharge placement for younger clients that allow for both a high level of continuity of care and services provided in a developmentally appropriate setting.

What it means to have "TAY" services varies by agency. Some agencies may engage in therapy following a specific model, such as the Transition to Independence Process (TIP) framework (Clark & Hart, 2009; Dresser, Clark & Deschênes, 2015), an evidence-supported model to support planning across five transition domains. In larger agencies, TAY services may be conceptualized as a set of many different programs, some which may vary by population (e.g., foster youth, youth experiencing homelessness, LGBTQ youth) and others that focus on the type of service (e.g., supported employment, independent living skills). Santa Clara County, CA has a continuum of services for this age population (Exhibit III-13). Their Raising Early Awareness Creating Hope (REACH) program uses the CSC model PIER and serves youth between 10-25 who exhibit any early warning signs of psychosis (i.e., are clinically high risk)[9] or have recently been diagnosed with psychosis.[10] REACH is less intensive than Wraparound Services and their Full Service Partnership program, but more intensive than outpatient services such as drop in services, general outpatient services, and the Young Adult Transition Team (YATT). The YATT in particular is well positioned to serve graduates of REACH, since it is a team-based approach to providing individual, family, and group therapy in addition to medication services, as well as intensive case management services; in other words, a similar but less-intense version of PIER.[11]

Exhibit III-13. Example of Integration of an Early Intervention Program Within a TAY Framework, Santa Clara County, CA



[9] See https://www.sccgov.org/sites/bhd/info/CYF/Documents/REACH%20-%20Psychosis/REACH%20BROCHURES/starlight-reach-broch-eng-06-2011.pdf.

[10] See https://momentumforhealth.org/youth-early-intervention.

[11] See https://www.sccgov.org/sites/bhd/info/CYF/Documents/bhsd-tay-prog-overview-ppt-06-01-18.pdf.

Assertive Community Treatment (ACT). As discussed in Section III-B in the context of level of services, ACT programs have a role in the discussion about transitions from CSC because they are one of the obvious choices for providing a *higher* level of services than offered through a CSC program. The ACT model, which is now more than 40 years old, was designed to meet the needs of individuals with severe mental illness who could not be adequately served through other types of mental health services, such as in general outpatient clinics (Bond et al., 2001). ACT and CSC programs have many components in common: Both are team-based, client-centered, involve community-based contact, flexible services and varying levels of care that are responsive to the clients' changing needs over time. However, eligibility criteria for a traditional ACT program is typically based on severity criteria evidenced by emergency room, hospital or crisis stabilization unit visits; experiencing significant difficulty with daily living, or failure to keep appointments or comply with medication regiments. Eligibility criteria for CSC programs, in contrast, is based on eligible diagnoses, duration of untreated psychosis, and age (Westat, 2019). Another major difference between the two programs is that CSC programs are generally described as time-limited whereas ACT programs are explicitly intended to be time-unlimited--so much so that having a no-discharge policy is one of the indicators of having high fidelity to the ACT model (Teague et al., 1998). As noted previously, ACT services seem appropriate for individuals discharged from CSC programs who have failed to respond positively to the CSC programming. However, it is a transition to a level of care that clients may also perceive to be disheartening to hopes for recovery.

ACT programs for TAY are a service route that could potentially offer an alternative to adult-focused ACT services. The structure of these youth ACT or "ACT-TAY" teams largely mirror those of the CSC framework, and in some cases, may have even more specialized positions within the team, such as an addiction professional and registered nurse. Core services can also mirror those of a CSC team. With a focus only on youth, ACT-TAY teams overcome one of the most frequent criticisms of transitioning CSC graduates to regular ACT services, which is that many ACT participants are individuals with significant disability associated with their mental illness, are older, and may present an overly negative and discouraging recovery outlook to young adults.

There is no centralized list of ACT programs in place for TAY, but at least a few systematic efforts are underway, for example, the State of Minnesota operates multiple sites (see box) and the Teens Need Transition program, located in Phoenix, Arizona, draws from both the TIP and ACT models.[12] In Missouri, CSC programs are called ACT-TAY, and the program simultaneously serve both individuals with and without FEP. Even if agencies are not able to establish separate ACT programs for youth, this approach can potentially help modify existing ACT models to be more youth friendly and serve as a more palatable and appropriate post-transition placement. Current prospective research underway in the Netherlands is specifically testing the effectiveness of a youth ACT model called Youth Flexible Assertive Community Treatment (Broersen et al., 2020), a study that will expand the empirical base for this approach.

[12] See https://www.touchstonehs.org/outpatient-services/transition-age-youth/.

Example Approach to Youth Assertive Community Treatment (ACT)
Minnesota

The State of Minnesota supports Youth ACT programs in four agencies, covering a total of 12 counties. Services are provided by a multi-disciplinary team and are available 24 hour per day, 7 days a week for as long as the client requires this level of service.

Youth ACT Team

- Mental Health Professional
- Licensed alcohol and drug counselor trained in mental health interventions
- Certified Peer Specialist
- Registered Nurse certified in psychiatric or mental health care or board-certified child and adolescent psychiatrist

Additional members may include:

- Additional mental health professionals
- Vocational specialist
- Educational specialist
- Mental health practitioners
- Mental health case manager
- A housing access specialist

Youth ACT Services

- Individual, family, and group psychotherapy and skills training
- Crisis assistance
- Medication management and education
- Mental health case management
- Medication education
- Care coordination with other providers
- Consultation and coordination with the recipient's support network, employer or school
- Coordination with, or performance of, crisis intervention and stabilization services
- Transition services
- Integrated dual disorders treatment
- Housing access support

Source:
https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS16_181612#cs

IV. OPPORTUNITIES & SUMMARY

This environmental scan has summarized a range of published and unpublished literature. It included recent state and program surveys as well as data from the national evaluation of CSC programs to describe the range of existing approaches to continuity of services after a client participates in a CSC program. This scan also identified selected areas where CSC programs are implementing innovative practices to facilitate post-CSC services. This includes the focused effort in Pennsylvania to examine different models of step-down services and payment options; programs such as in Missouri that coordinate with TAY services; and models that propose a flexible five-year window of services such as in Columbus, Ohio, among many others. We also presented challenges and opportunities. Below we highlight several areas that represent additional emerging opportunities related to transition practices, followed by a summary.

A. Emerging Opportunities

Telehealth

In treatment of psychosis, telehealth is a rapidly emerging modality (e.g., Lal et al., 2020; Santesteban-Echarri et al., 2020), and is one that has direct relevance and promise as a mechanism for ongoing care. Evidence suggests that telepsychiatry has been effectively used to conduct neurological assessments (Stain et al., 2011) and that clinical benefits do not appear to be greatly compromised (Santesteban-Echarri et al., 2020). For clients graduating from a CSC program, use of telehealth with CSC staff would provide relational continuity and could address several challenges. The Psychosis Evaluation and Recovery Center in Philadelphia, for example, has used teletherapy for case management and therapy following an initial period of in-person services (Hurford, 2019). In areas with limited providers or where there are long waits to see a prescriber, telepsychiatry can ensure that the client is receiving appropriate care. In situations where a client is reluctant to leave the program, telepsychiatry could provide the bridge a client needs to subsequently transfer to community-based providers. Telepsychiatry is known for its use in rural areas and settings where transportation is a challenge; given that a sizeable percent of CSC programs reported transportation issues to be a concern in their efforts to ensure transitions, use of technology could alleviate the problem of clients not being able to physically travel to a prescriber.

With the COVID-19 pandemic, therapists in many states have had no choice but to adapt telehealth practices, even if these were not in place previously. Temporary legislation was enacted in 2020 to support this; the Centers for Medicare & Medicaid Services lifted regulations related to coverage of telehealth under Medicare to provide coverage at the same rate for telehealth as in-person visits, allowed services to take

place in the clients' home, and permitted all Medicare eligible providers (including clinical psychologist and social workers) to provide telehealth services.[13] As a result of developing the technological infrastructure during this period, telehealth may become more widespread even after clients can resume in-person visits.

Alumni Programs

Peer support has increasingly become an active part of CSC programs. Within the MHBG study sites, a total of 25 of the 36 programs had a peer support component, and five of these initiated a new peer support component between just the first and second year of the study (Westat, 2019). While related, far less information is available about alumni programs, since many CSC programs do not yet have a significant number of graduates to generate alumni groups. There are still some emerging examples of how this is taking place in the United States. In the POTENTIAL Program in Connecticut, for example, staff continue to offer services after graduation, including weekly support groups, telephone support, family education groups and regular outings and field trips. In Rhode Island, a CSC program offers groups that graduates can attend, such as art therapy, DBT, nutrition, and an Adventure Based Therapy group. OnTrackNY runs a Youth Council that gives both current participants as well as graduates the opportunity to provide guidance to OnTrackNY leadership. Similarly, EASA operates the Young Adult Leadership Council, which is designed both as a mechanism to shape EASA policy and practice, as well as a way to network with peers, have an outlet for self-expression, and provide a healing and growth-oriented experience. Anecdotally, programs noted that clients enjoy coming back and connecting with teams. Even if this occurs informally and without any clinical intervention or formal council such as in OnTrackNY and EASA, alumni programs can help graduates stay engaged and practicing mutual support may also foster greater treatment engagement with prescribers and other clinicians they are seeing. In this respect, alumni groups may be a powerful tool to facilitate successful transitions.

Early Psychosis Intervention Network (EPINET)

In September 2019, the National Institutes of Mental Health (NIMH) awarded research grants to five CSC "hubs" around the country, as well as a National Data Coordinating Center, as part of a learning health care system for the treatment of early psychosis, called the Early Psychosis Intervention Network (EPINET). EPINET is developing a core assessment battery, which each hub will then employ with clinics in their own network. The core assessment battery includes domains such as functioning, cognition, symptoms, and recovery. In addition, the battery includes a question about the reason for discharge and location of referral. The core assessment battery will be made available to any interested CSC program through the EPINET National Data Coordinating Center. EPINET could be encouraged to actively study the discharge process and outcomes that are associated with differential practices. These are critically important questions if the field is to realize the anticipated benefits of early intervention.

[13] See https://www.ama-assn.org/delivering-care/public-health/key-changes-made-telehealth-guidelines-boost-covid-19-care.

EPINET holds great promise to help identify potential predictors of successful outcomes.

Telepsychiatry itself has numerous challenges, of course, which have been well-articulated elsewhere (e.g., Shore, 2013). These include ensuring that psychiatric emergency service protocols are well-established; maintaining awareness of communication style (such as sustaining eye contact) and transmission delays in sound; and adapting the therapeutic style to overcome potential feeling of clinical remoteness, among others. Prior to emergency legislation enacted under COVID-19, telehealth was not always billable, depending on the location of the client, for example, only 19 states had Medicaid policy that allows for reimbursement of services in the home (Center for Connected Health Policy, 2019). Tennessee, for example, was not one of these, and while the CSC program used telehealth regularly between clinics in the state, the team noted that they could not regularly use it when the client is in his or her home. While the current allowances for telehealth payment through Medicaid enacted under COVID-19 may eventually reverse, the upcoming months will provide important data on use of this approach to facilitate transitions.

B. Summary

1. Terminology related to transitions from CSC programs is just emerging. In the context of CSC transitions, step-down typically means a reduction in either the frequency or intensity of services, or both, as well as a shift in focus. Step-down services can also vary in a wide number of other respects, such as whether the same or different staff provide services after discharge from the CSC program or the services are provided within the same or different agency.

2. Based on a scan of approximately 50 CSC programs, there are consistent patterns that programs follow with respect to the duration of their program, the nature of step-down/transitional services available, and the location of placement following the transition. Among CSC programs included in the scan, the most common pattern was for programs to work with a client for approximately two years, followed by a referral for services either within the same agency or the community. Clients are aided in making a transition, such as through a warm hand-off and other preparatory strategies. A small number of programs have begun incorporating step-down services within the CSC program, either formally or informally. In some sites, CSC programs are identifying the program length to be up to five years, and allow the intensity of service use to fluctuate within that period.

3. Between 44 percent and 58 percent of CSC programs (N=74) refer clients to programs within their own agency following completion of CSC services. Most programs reported transitioning clients to services that were a lower level of intensity than the CSC program, but acknowledged that some clients require a

higher level of care. In these situations, ACT was the most frequent placement identified.

4. Across a range of sources, programs reported the typical program length to be two years, but frequently noted that this amount of time seems too short for many clients.

5. The OnTrack, EASA and FIRST CSC programs have all developed guidance to assist in transition planning. Many of the criteria that programs use are based on client progress in treatment, functioning and stability of the clients. Client perception of readiness and client preference are critical to consider, but were less frequently mentioned by programs as criteria for determining readiness to transition.

6. Two common strategies to ease the process of transition are establishing connections with the receiving provider and continuing to maintain contact with the client even after discharge. Reimbursement policies and demands on staff time can make continued client contact a challenge, however.

7. Above all other challenges in facilitating an effective transition, CSC programs identified a lack of appropriate services as the greatest barrier. Survey respondents regarded many clinicians in the community as ill equipped or unwilling to serve clients with FEP. Respondents also commonly cited differences between the CSC and standard community outpatient programs, leading to clients' dissatisfaction and subsequent dropping out. Finding psychiatrists or other providers who will accept either Medicaid or commercial insurance, as well as who are willing to manage clients taking Clozapine, further limits discharged clients from obtaining affordable community care. Respondents identified transportation to services as a challenge equal to that of funding. Another challenge, though not as common, are factors related to client willingness to leave and client willingness to initiate new services.

8. States are involved in transition-related aspects of CSC services through different mechanisms. Twenty states provide guidance for program length, and nine states provide hard limits.

9. Funding challenges for continuity of care services are notable. Medicaid policies, which are determined at the state level, pose a challenge in conducting certain transition-related activities, such as those that do not involve face-to-face contact. There are both state and national efforts to implement changes to reimbursement policies for both public and private insurance that would allow a tiered and bundled rate of reimbursement for CSC services, which would provide coverage for some of the services that are currently difficult to reimburse and could likely also support step-down services that are integrated into CSC programs. Based on these initial efforts and calculations such as those from New York (Smith et al., in press), a cost based, bundled payment mechanism appears warranted for CSC services

and could be constructed to assure that transition services can be delivered. The impact would be sizeable, since many individuals served in CSC programs are privately insured. Additional actuarial work regarding the varying costs of the programming as clients pass through the CSC program would be very helpful. Having data on the differing costs and variance in costs for FEP clients would enable a bundled payment rate that could support the differential intensity of services both within the CSC program window and through the transition.

10. Although not widespread, other existing federal, state and local programs have intersected with CSC transition services. CCBHCs are being used as a mechanism to support post-transition services in some locations, and SOC grants offer potential for enhanced collaboration across agencies that serve youth. ACT is frequently used for individuals who need a higher level of care after a CSC program, although it is not regarded as an ideal placement by providers. TAY services and ACT-TAY programs warrant further investigation as a potential option offer a promising post-CSC option for younger clients, since these services provide support in the areas most essential to young adults. Additional federal guidance regarding the use of waivers, home and community-based services (HCBS) and CCBHCs would be helpful to the field.

11. Telehealth is one area of service provision that is rapidly transforming as a result of the COVID-19 pandemic. While primarily used by CSC programs serving more rural populations, telehealth could be used during the transition phase of CSC programs as a form of step-down services. If Medicare and private insurers continue to provide coverage for home-based services post-COVID, then telehealth may become an important post-discharge option, especially since many clinics have now acquired and become fluent in the use of telehealth technology.

12. To date, there has not been sufficient collection and analysis of post-discharge data to definitively identify specific promising practices based on specific approaches to transitions. While challenging, some programs are starting to develop mechanisms to track participants past discharge, which will greatly move the field forward. The case studies that are planned as part of this study are also designed to highlight innovative and exemplary approaches to continued care.

C. Conclusion

A focus on transitions and post-discharge placement is clearly warranted based on the concerns regarding the long-term benefits of early intervention programs in conjunction with the rapid expansion of CSC programs in the United States. The current environmental scan highlights both the efforts undertaken and challenges that programs and states face in ensuring appropriate services. CSC programs vary in their adherence to program time limits, with a trend towards greater flexibility and more than two years duration. However, since the ultimate goal is to serve all cases, and since program funding is likely to remain limited from both commercial and public insurers, efficient

movement through the CSC program is desirable. The overarching goal of the current study, which includes exemplar programs, is to identify practices and policies that may help programs better achieve the balance of serving clients for as long as needed to solidify gains before discharge, while also maintaining a flow of new clients into the program.

This environmental scan focused on a variety of the transition process--including location of services following discharge and level of services provided, program length, determining readiness, and practices to support transitions. We integrated data from both SMHAs and CSC program staff, as well as unpublished sources of information to compile a current snapshot of these processes in the United States. There are several limitations of the current scan worth noting. One of the sources for this study was the MHBG Study, and in particular, discussions with staff about their transition and post-discharge services. Data are not available from all sites, since these questions were added after some site visits had taken place. Among sites with data, the discussions varied in depth and therefore the amount of detail available varies. In addition, the data were collected approximately a year prior to this report, and it is possible that programs have changed their practices since that time. This has particular relevance for Appendix C, in which sites are identified by name. These descriptions should be considered a snapshot of a particular point in time, based on varying data sources. An additional limitation is that data from the NRI/NASMHPD CSC Needs Assessment Survey are only available from 50 programs. Given this limited number of programs, we caution against generalizations based on those data.

Ultimately, a key takeaway for every aspect of transition covered in this scan is that there is no *one* ideal model for post-discharge services. The myriad of contextual factors that influence this process at the state, community and program level all create a set of constraints. Within these constraints, the individual needs of a client then must drive each step of the process. Federal leadership in CSC programming has had a profound, positive impact on the development of CSC programs. Continued leadership in the financing of CSC, transitions, and step-down services is likely to be critical in sustaining this movement and realizing the ultimate benefits of EIP. Many interesting and innovative suggestions are emerging from the field and have been summarized here. Further support for these efforts and for ascertaining their ultimate effectiveness is critically important.

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APPENDIX A. KNOWN EIP/CSC RESOURCES

- National Association of State Mental Health Program Directors (NASMHPD)
- Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS)
- PEPPNET
- Early Assessment & Support Alliance (EASA)
- NAVIGATE Consultants
- OnTrackNY
- Portland Identification and Early Referral (PIER) Program
- Orygen, the National Centre of Excellence in Youth Mental Health (Australia)
- First Episode Psychosis (FEP), the National Council for Behavioral Health
- Prevention and Early Intervention Program for Psychosis (PEPP-Montréal)
- Opus Copenhagen
- The Evidence-Based Practice Center, MD
- Early Psychosis Intervention (EPI)
- MindMap
- NAMI
- Strong 365

APPENDIX B. QUESTIONS FROM INTERVIEWS AND SURVEYS

MHBG 10 Percent Set-Aside Study Interview Questions Related to Transitions

1. What are the criteria for completing your CSC program?

2. Does [program name] have a step-down program or any services for clients after they have participated in the program?

3. Have you had any clients "graduate" or leave the program over the past year? *If yes*:

    a. Did they leave because they were doing so well, or did they hit some type of eligibility limit (or some other reason?)

    b. Was there anything that the program did to help with the transition?

    c. Do you have any contact with clients who have left the program?

NRI-NASMHPD State Mental Health Authority Survey

1. Has your state set limits or expectations regarding how long CSC programs should keep First Episode Psychosis (FEP) clients in services before graduation/transition from the CSC Services?

   ☐ Our SMHA has set **hard limits** (such as 2 years/24 months) for FEP clients who should then be discharged from the CSC Program.

   If yes, how many months is this limit?

   ☐ Our SMHA has a **recommended limit** for how long FEP clients should be in CSC services, but it is up to individual programs to determine when to graduate a client from CSC services.

   If yes, how many months is the recommended limit?

   ☐ Our SMHA **has not set limits** or expectations for how long FEP clients should be in a CSC program.

   If you answered "c" to the question above, i.e., your SMHA has NOT set limits/expectations for how long FEP clients should be in CSC services, please answer question 2 below, otherwise skip to question 3.

2. Have CSC programs in your state set their own limits on how long FEP clients can be enrolled in their CSC services?

   ☐ Yes, **All** programs have set limits (Answer a and b below)

   ☐ Yes, **Some** programs have set limits (Answer a and b below)

   ☐ No, **None** of the programs have set limits to our knowledge (Skip to question 3)

   a. What is the limit or range of limits in months: Low to High months

   b. Are the CSC programs that have set limits **flexible** in enforcing this limit?

   ☐ Yes ☐ No If yes, please describe:

3. Has your SMHA either developed services or recommended service packages for FEP clients graduating out of CSC services? ☐ Yes ☐ No

   If yes, please describe what the service package is to transition clients from CSC services (or attach copies of your recommended service packages):

4. If your SMHA has **NOT** developed services or recommend service packages for FEP clients graduating from CSC services, are you aware of any transition plans that your CSC programs have developed for graduating FEP clients?

   ☐ Yes ☐ No

   If yes, please describe:

5. Please describe any barriers to continuity of care that you have identified for clients who are graduating from CSC services.

6. Please feel free to provide any additional comments on this topic.

NRI-NASMHPD CSC Needs Assessment Survey Transition-Related Items

1. Do you have any practices related to transitions or continued care of services that you feel have been particularly effective or beneficial for clients?

   ☐ Yes ☐ No

   If yes, please describe:

2. Which of the following **most closely** describes your program with respect to addressing transitions for clients who are either 'graduating' or have reached your program's service limit? *Please select one*.

   ☐ We have not yet needed to address transitions (e.g., our program is very young; clients have not been enrolled very long)

   ☐ Clients do not need to transition elsewhere; they remain in our CSC program as long as needed

   ☐ If a transition is needed, we often refer clients to services within our agency (although services may not be the same as within the CSC program)

   ☐ If a transition is needed, we often refer clients to community-based providers, outside our program/agency

   ☐ Other, please describe:

3. Please indicate whether any of the following have been a challenge in your effort to transition clients out of your program. *Check all that apply*.

   ☐ Lack of providers that specialize in psychosis

   ☐ Long wait list for providers with psychosis expertise

   ☐ Limited therapists with expertise in psychosis/who can provide psychosis-focused therapy

   ☐ Reluctance of providers to accept clients with a diagnosis of psychosis

   ☐ Lack of prescribers who are knowledgeable about best practices for prescribing for young adults living with pychosis

   ☐ Lack of supported education/employment services in usual care settings

   ☐ Lack of other key services in usual care settings (e.g., peer services; assertive outreach; case management)

   ☐ Providers unable or unwilling to provide care beyond psychopharmacology

   ☐ Differences in therapeutic environments between outpatient providers and CSC models (e.g., strict “no-show” policies)

☐ Problems related to adequate service coverage for privately insured clients

☐ Problems related to adequate service coverage for Medicaid/Medicare clients

☐ Lack of transportation for clients to reach outpatient services

☐ Client resistance

☐ Other, please describe: