Continuity of Care Following Coordinated Specialty Care

Abram Rosenblatt, PhD
Tamara Daley, PhD

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Study Team

Westat/University of Maryland

- **Tamara Daley**
  Project Director
- **Abram Rosenblatt**
  Principal Investigator
- **Howard Goldman**
  Senior Advisor
- **Preethy George**
- **Melanie Chansky**

Advisory Panel

- **Lisa B. Dixon**
  New York State Psychiatric Institute
- **Nev Jones**
  University of South Florida
- **Ted Lutterman**
  National Association of State Mental Health Program Directors Research Institute
- **David Shern**
  NASMHPD Senior Public Health Advisor

Office for the Assistant Secretary of Planning & Evaluation (ASPE), Health & Human Services

- **Kristina West**
- **Joel Dubenitz**

Objectives

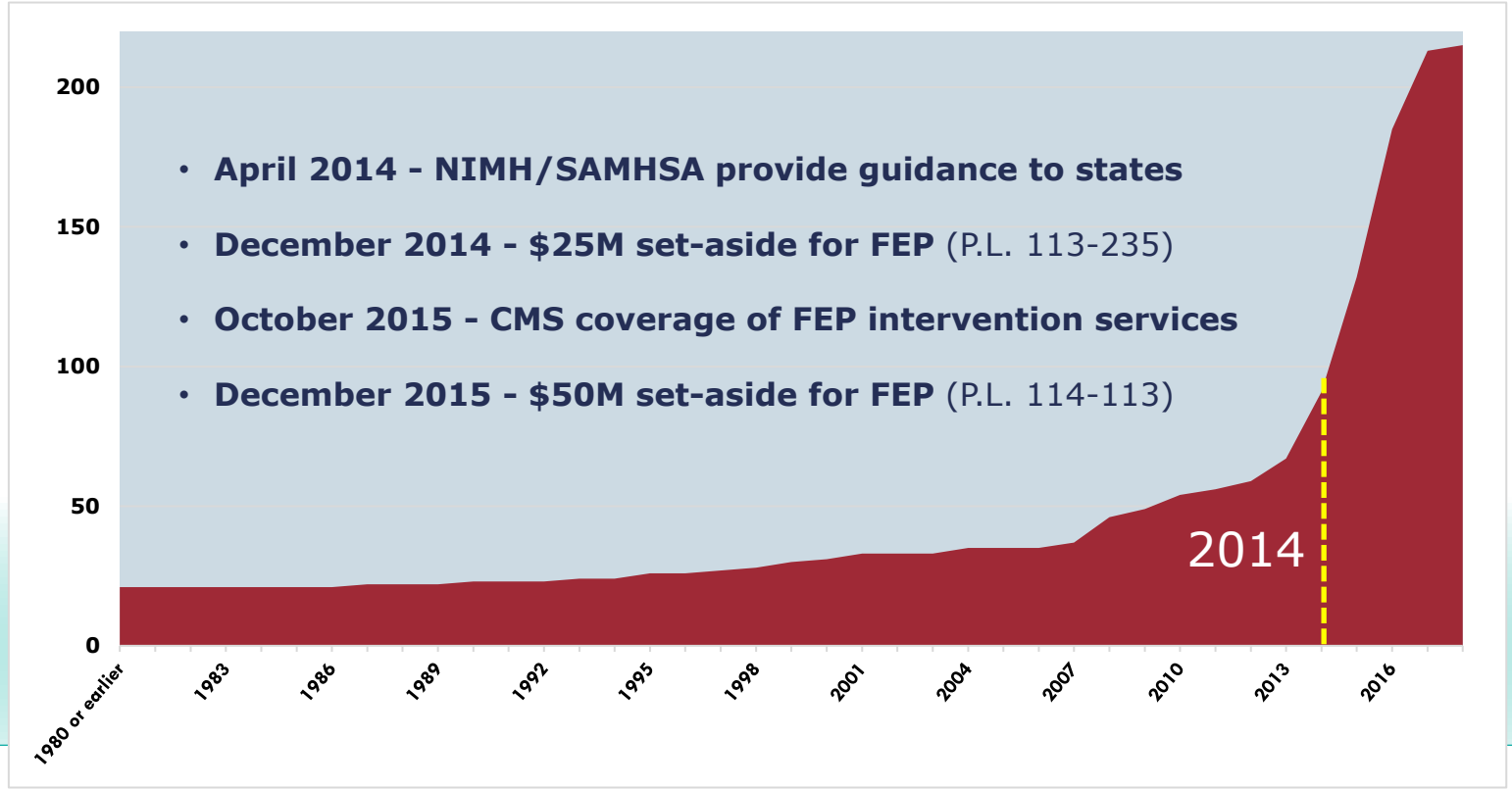
1. Background: How and why this project came about & study methods
2. The range of existing approaches to continuity of care services
3. Opportunities and challenges
4. Policy implications
5. Areas for future research

Background

Coordinated Specialty Care (CSC)

- Team-based early intervention for first-episode psychosis that combines evidence-based services (e.g., therapy, pharmacotherapy, supported employment & education, family education and support, case management)
- Typically around 2 years in length
- A large increase in new CSC programs in 2014, following Mental Health Block Grant set-aside funding

The Growth of CSC Programs



What about transitions *out* of Coordinated Specialty Care??

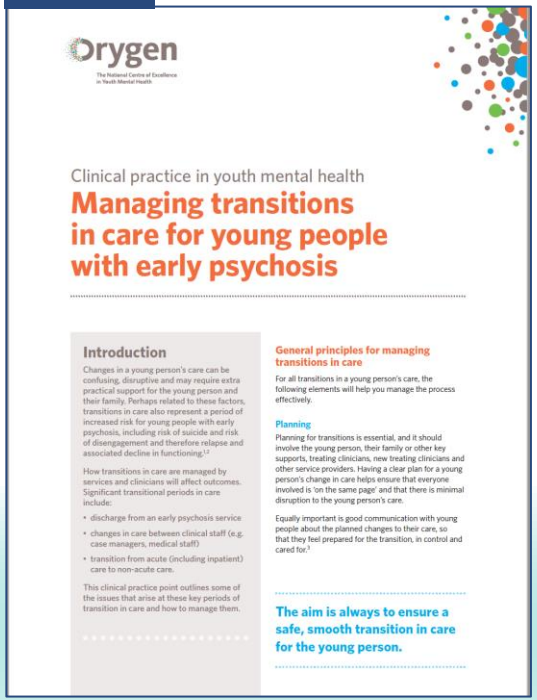
2008

> 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)

2014

> “The team provides a critical time intervention 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)

2015



Orygen
The National Centre of Excellence in Youth Mental Health

Clinical practice in youth mental health

Managing transitions in care for young people with early psychosis

Introduction

Changes in a young person's care can be confusing, disruptive and may require extra practical support for the young person and their family. Perhaps related to these factors, transitions in care also represent a period of increased risk for young people with early psychosis, including risk of suicide and risk of disengagement and therefore relapse and associated decline in functioning.[1,2]

How transitions in care are managed by services and clinicians will affect outcomes. Significant transitional periods in care include:

- discharge from an early psychosis service
- changes in care between clinical staff (e.g. case managers, medical staff)
- transition from acute (including inpatient) care to non-acute care.

This clinical practice point outlines some of the issues that arise at these key periods of transition in care and how to manage them.

General principles for managing transitions in care

For all transitions in a young person's care, the following elements will help you manage the process effectively.

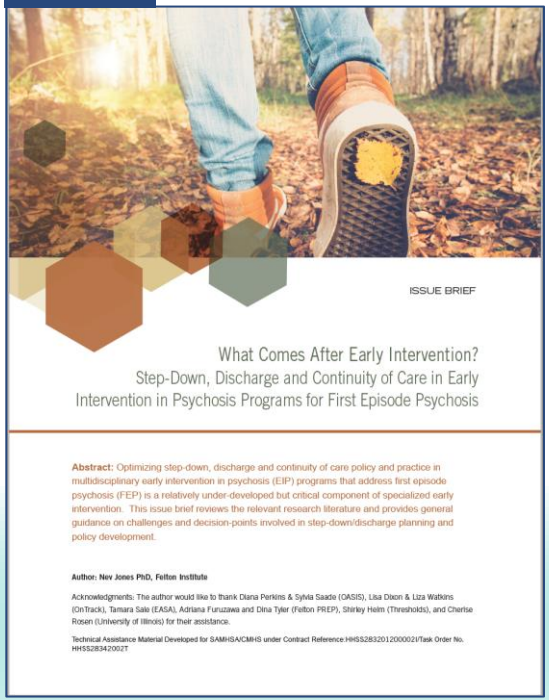
Planning

Planning for transitions is essential, and it should involve the young person, their family or other key supports, treating clinicians, new treating clinicians and other service providers. Having a clear plan for a young person's change in care helps ensure that everyone involved is 'on the same page' and that there is minimal disruption to the young person's care.

Equally important is good communication with young people about the planned changes to their care, so that they feel prepared for the transition, in control and cared for.[3]

The aim is always to ensure a safe, smooth transition in care for the young person.

2016



ISSUE BRIEF

What Comes After Early Intervention? Step-Down, Discharge and Continuity of Care in Early Intervention in Psychosis Programs for First Episode Psychosis

Abstract: Optimizing step-down, discharge and continuity of care policy and practice in multidisciplinary early intervention in psychosis (EIP) programs that address first episode psychosis (FEP) is a relatively under-developed but critical component of specialized early intervention. This issue brief reviews the relevant research literature and provides general guidance on challenges and decision-points involved in step-down/discharge planning and policy development.

Author: Nev Jones PhD, Felton Institute

Acknowledgments: The author would like to thank Diana Perkins & Sylvia Saade (OASIS), Lisa Dixon & Liza Watkins (OnTrack), Tamara Sale (EASA), Adriana Furuzawa and Dina Tyler (Felton PREP), Shirley Helm (Thresholds), and Cherise Rosen (University of Illinois) for their assistance.

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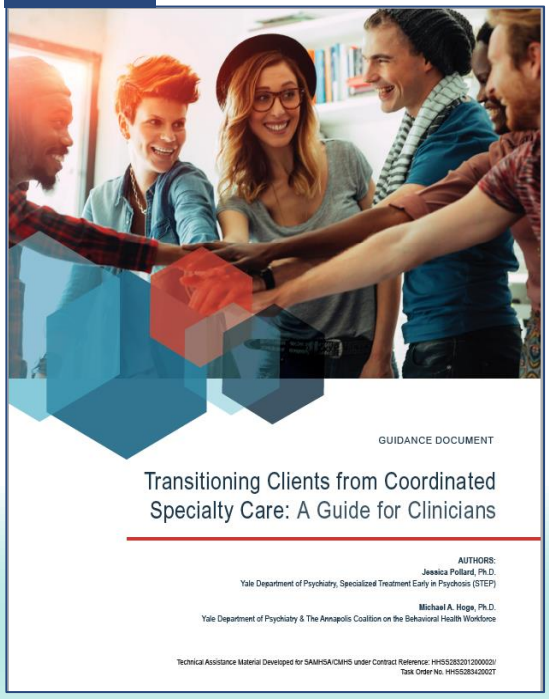
2018



GUIDANCE DOCUMENT

Transitioning Clients from Coordinated Specialty Care: A Guide for Clinicians

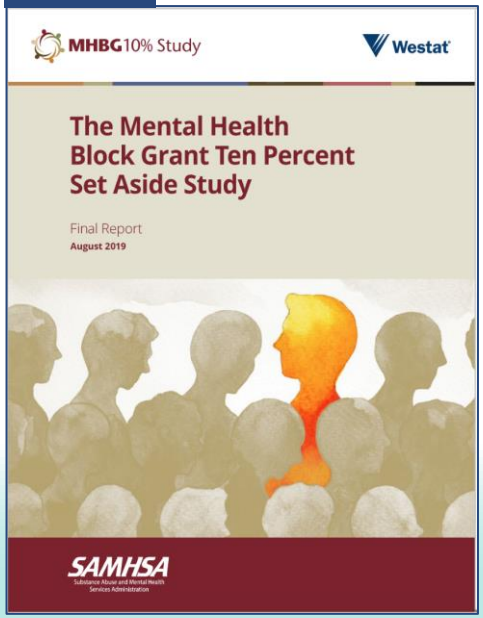
AUTHORS:
Jessica Pollard, Ph.D.
Yale Department of Psychiatry, Specialized Treatment Early in Psychosis (STEP)

Michael A. Hoge, Ph.D.
Yale Department of Psychiatry & The Annapolis Coalition on the Behavioral Health Workforce

Technical Assistance Material Developed for SAMHSA/CMHS under Contract Reference: HHSS283201200002I/ Task Order No. HHSS283420002T

What we learned from the MHBG Ten Percent Set Aside Study

2019



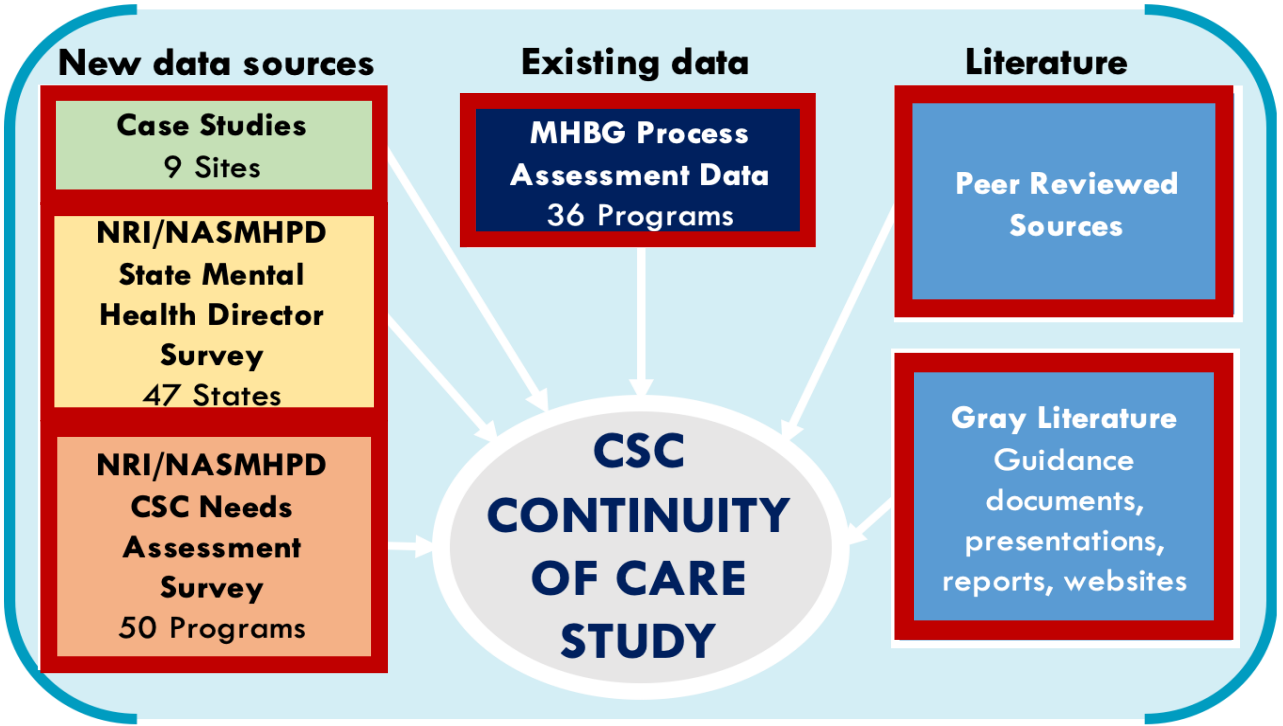
- **Most clients complete their program in between one and three years**
- **Very limited formal post-discharge programs (e.g., "step-down" programs) available**
- **Frustration about lack of "routine community service" options**
- **Concerns about relapse**

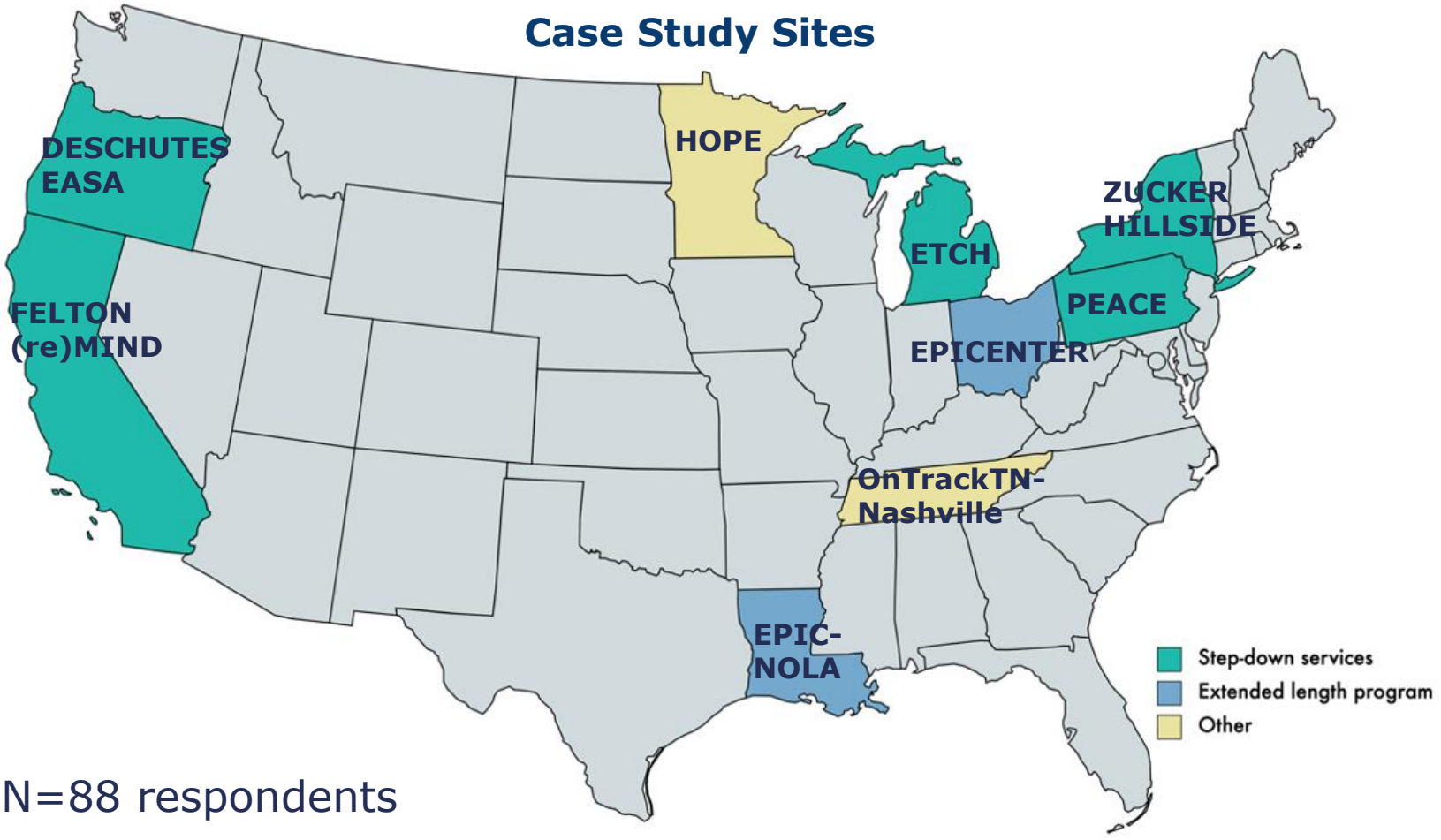
We also know…

- CSC teams commonly identify **post-treatment placements in the community** as a challenge (Jones et al., 2020 using MHBG Study data; Jones, 2016; Pollard & Hoge, 2018)
- Studies from outside the U.S. suggests that participants who receive services for a **greater number of years** show:
  - Longer 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)

Continuity of Care After a Coordinated Specialty Care Program

Methodology





N=88 respondents

Case Study Sites

Program	Location	Date CSC program started	Approximate program census	Type of program setting	Serves adults only or both children and adults	Age range served	Clinical team size	EPINET Site?
EPICENTER	Columbus, OH	2015	107	University	Both	15-35	24	N
EPIC-NOLA	New Orleans, LA	2015	156	University	Adult	12-35	10	**Y**
PEACE	Philadelphia, PA	2015	115	CMHC	Adult	15-30	13	**Y**
ETCH	East Lansing, MI	2014	51	Other	Adult	15-30	9	**Y**
Zucker Hillside	Glen Oaks, NY	2013	75	Hospital	Both	16-30	10	**Y**
Felton (re)MIND®	San Mateo, CA	2012	45	CMHC	Both	14-35	10	**Y**
Deschutes EASA	Bend, OR	2008	35	CMHC	Both	12-29	13	N
OnTrackTN FEPI	Nashville, TN	2016	21	CMHC	Both	15-30	6	N
HOPE	Minneapolis, MN	2017	50	Hospital	Both	15-40	9	**Y**

Broad content areas of interviews

- Program structure and philosophy
- Staffing and caseloads
- Origin of general approach
- Program length
- Integration in organization

Description of approach

- Preparation for transitions
- Post-discharge placements
- Contact and communication after discharge
- Advantages/strengths of continuity of care structure
- Areas for improvement of continuity of care structure
- Recommendations to other programs

Detail of practices

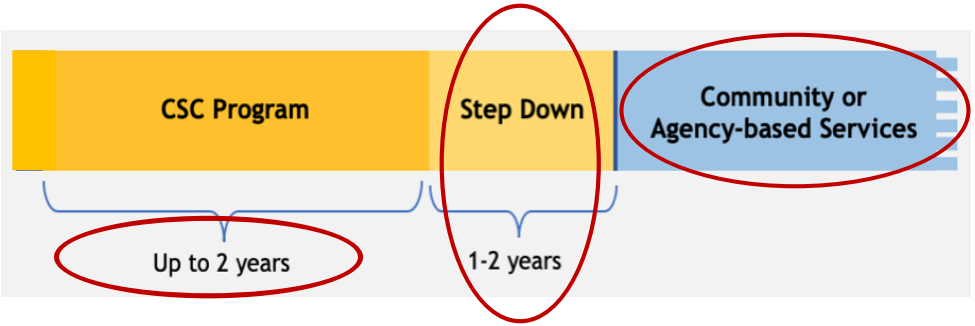
- Population served
- Community factors
- State involvement

Context

Approaches to continuity of care

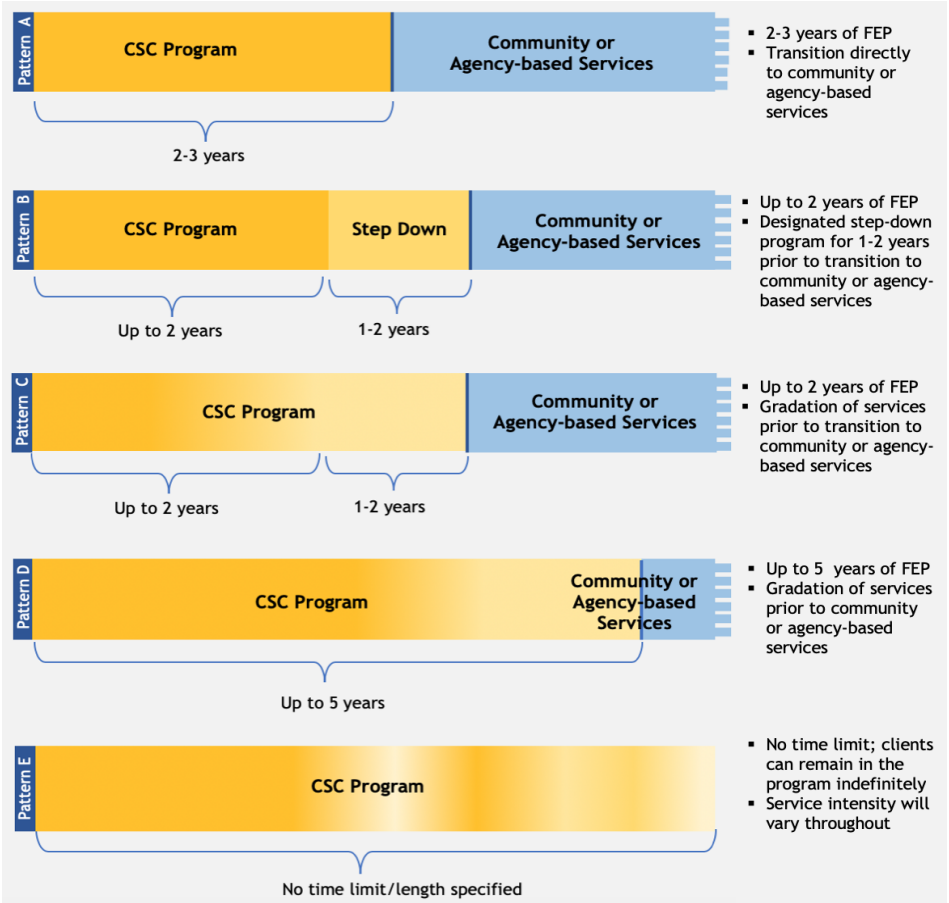
Factors that influence how CSC programs handle transitions

1) Length of the "core" CSC program;
2) The nature of step-down/transitional services available; and
3) Whether the placement following the transition is within the broader community or the same organization that provided the CSC services.



Five common patterns

Common CSC Patterns Related to Transitions



N=25 **46.3%** OnTrackTN FEPI

N=8 **14.8%** PEACE, EASA Deschutes, Felton (re)MIND®, ETCH, Zucker Hillside

N=9 **16.7%** HOPE

N=7 **12.9%** EPICENTER

N=5 **9.2%** EPIC-NOLA

Extended Length Models: Case Study Examples

EPICENTER & EPIC-NOLA

Rationale

- Maintain gains, based on OPUS
- Provide appropriate and needed care in a setting with limited services; highly traumatized and distrustful population

Commonalities

- Local control over behavioral health
- Larger client census
- Longer permitted DUP
- Linked with a university, rely on residents
- No dedicated SEE position

Differences

- State penetration of programs
- Population served
- Degree of integration
- Receipt of MHBG funds

Perceived Advantages

Clients and families

- Flexible to match individual needs of client
- Provide support through multiple developmental milestones
- Eliminate transitions during vulnerable times, reduced risk of drop-out at that time, no rupture in relationships
- Allow issues of trauma to emerge at natural points
- Relieves anxiety for families
- Greater sense of self-determination to come and go

Team members

- Can provide treatment without constraints of clinic policy re. discharge
- Know the client extremely well

Step-Down Approaches: Case Study Examples

PEACE, **ETCH**, **Zucker Hillside**, **Deschutes EASA**, and **Felton (re)MIND®**

Rationale

- Lack of community options; also limited options within organization
- Extend gains
- Serve broader populations

Commonalities

- Same location

Variability in Step-Down Programs

Characteristic of Step-Down Program	PEACE	EASA Deschutes	Felton (re)MIND®	ETCH	Zucker Hillside
	Step Up	*YAT*	*Alumni*	*NAV2GO*	*BOOST*
Serves clients in the same location vs. a different setting	Same	Same	Same	Same	Same
Major shift in focus during step-down vs. extension of CSC	Shift in focus	Extension	Extension	Shift in focus	Extension
Selective in who can attend step-down vs. admits all clients	Selective	All (within age range)	Selective	Selective	All (within age range)
Step-down can serve clients at the same level as the full CSC if needed vs. only at a lower level	Lower only	Same level if needed	Same level if needed	Same level if needed	Lower only
Step-down serves CSC population only vs. also serves others	Only CSC	Others also	Others also	Only CSC	Others also
Step-down serves all ages vs. limited age group	All ages	Up to age 25	All ages	All ages	Age 18+
Time limit to step-down services vs. unspecified length of services	Limit (time-based, 2 years)[a]	Limit (age-based)	Limit (time-based, 2 years)[d]	No limit currently defined[e]	No limit currently defined

Variability in Step-Down Programs

Characteristic of Step-Down Program	PEACE	EASA Deschutes	Felton (re)MIND®	ETCH	Zucker Hillside
	Step Up	*YAT*	*Alumni*	*NAV2GO*	*BOOST*
Staff members are same vs different					
Prescriber/Licensed Medical Provider	Same	Different	Same	Same	Different
Therapist	Different	Same	Same	Different	Likely different
Case Manager	Same	Different	Not a position	Not a position	Not a position
Supported Employment and Education (SEE) Specialist	Same	Different	Same	Different	Not a position
Peer Support Specialist	Same	Same	Same	Same	Not a position

Perceived Advantages

Clients and families

Many the same as extended length

- "Nearly seamless" transition process, avoids feelings of abandonment
- Sense of safety net, offers a "try-out" at lower level
- Provides a marker of success, sends a message about recovery

Team members

- Reinvigorates therapists to see payoff, success in step-down
- Easy to facilitate and communicate
- No anxiety about what will happen after graduation

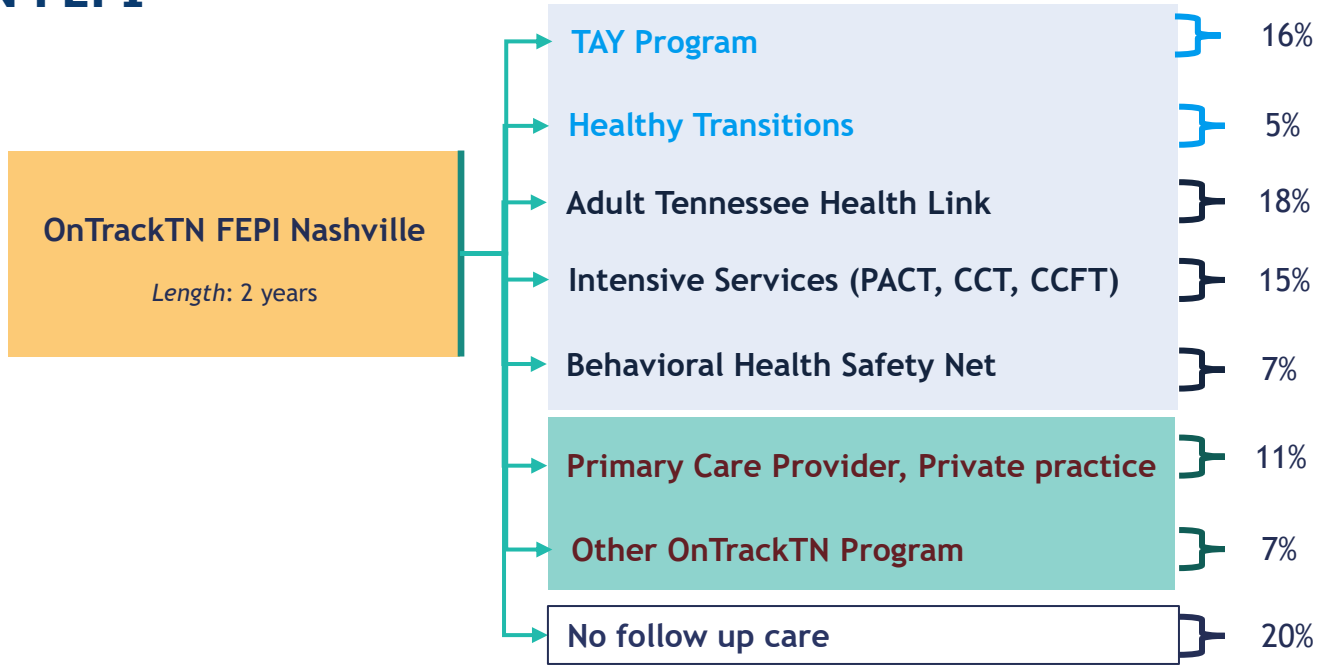
Other Approaches to Continuity of Care: Case Study Examples

OnTrackTN

- Two-year program
- Seven common post-discharge options within the same organization
- Two transition-age options

> “I think we've seen some really great transitions occur because of our ability to have those in-house conversations, to have relationships built across teams, across providers, to really make that as smooth a process as possible... so folks don't just fall off the map.

OnTrackTN FEPI



Location of services
Within organization
Outside organization

Youth vs Adult focus

Transition-Aged services

Adult services

Could be either youth or adult focused services

Other Approaches to Continuity of Care: Case Study Examples

HOPE

- Located within Hennepin Healthcare
- Approximately 1-3 years; not fixed
- "Internal" step-down
- Three groups: Engagement, active treatment, transition
- No standards or milestones
- Can move back up
- Allows staff more flexibility

> "We say, 'If we taper down and you're not ready for it, it's okay that you say you're not ready and we can move up again'…so it becomes more person centered, it's not so regimented.

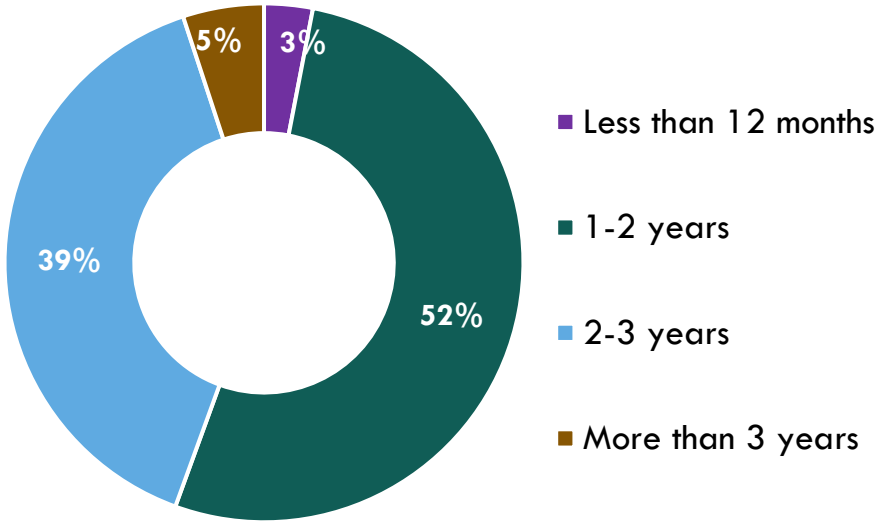
Program Length

Case Studies

OnTrackTN FEPI	2 years and must apply to state for an extension
Felton (re)MIND®	Typically 2 years
HOPE	Typically 1-3 years
PEACE	Typically 2 ½ years (with flexibility)
Zucker Hillside	Typically 2 ½ years (with flexibility)
Felton (re)MIND®	Typically 2 years
ETCH	Typically 2-5 years
EPICENTER	Up to 5 years, with clients able to leave and return anytime in that window
EPIC-NOLA	No defined program length

MHBG Survey (N=215)

91% - Average time to complete the FEP program is between 1 and 3 years



Perspectives on Program Length

- Approximately **three-quarters of respondents** favored either a 3-5 year model, or reported that the program should be tied to client need and not have a set length.

> I think it should be individualized. One of my mantras is, 'people before programs.' If we lose the person because we're trying to develop and deliver a particular structured intervention, and that doesn't have enough wiggle room to flex for the person who's actually engaging in the program, then I think we've got things backward.

> Four to five years gives a good sense of progress, you see growth happen. Two years feels too soon. Clients with slow progress don't make any headway… and then suddenly they have to start talking about discharge and termination.

> I don't know if there really even is a number that you can put on it. We certainly have folks that have needed more time and folks that probably would need a significant amount of intensive treatment and support. We also have folks who have needed less; it really does feel like a very individualized question.

Placement After Discharge

Refer to services within own organization

MHBG Study Sites: **44%** (N=16)

NRI/NASMHPD CSC Needs Assessment Survey: **58%** (N=22)

Participate in step-down program (among case study sites)

Early Treatment Program/BOOST	100%
Deschutes EASA/YAT	42%
Felton/(re)MIND® Alumni	30%
ETCH/NAV2GO	28%
PEACE/Step Up	17%

Funding

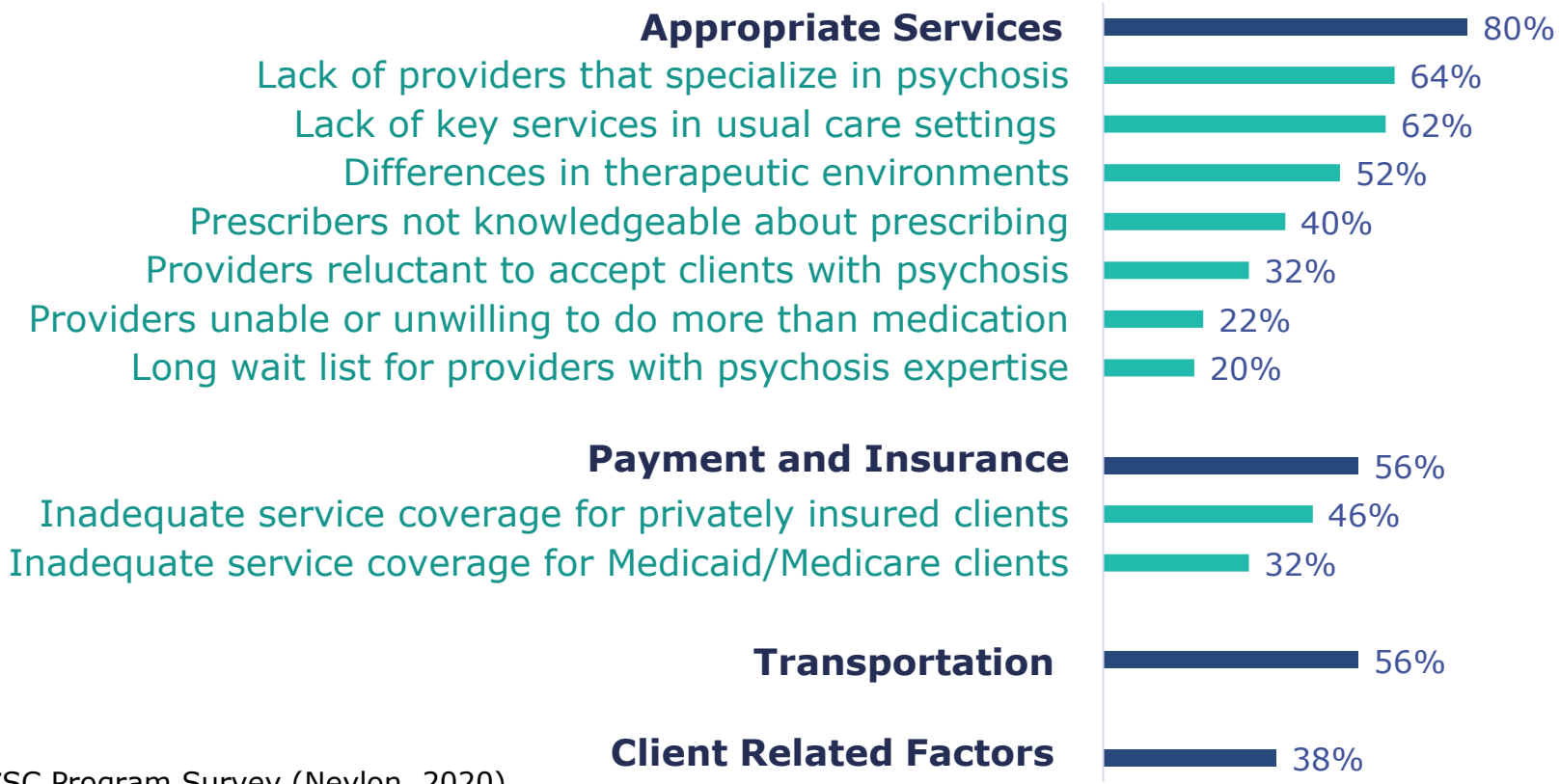
- Step-down and extended length programs are generally funded using the **same resources** as CSC programs
  - Medicaid reimbursement
  - Private insurance reimbursement
  - Block grants
  - County funding
- Funding and program length are linked
- Reimbursement gaps → Block Grant funds are critical
- Case rate models and tiered models are being explored
  - Unclear impact on post-transition programs

Opportunities and challenges in implementing different approaches to continuity of care

Key Transition Practices

1) **Discuss transitions early**
   - Early discussions instill hope
2) **Connect with receiving providers**
   - Warm hand-offs
   - Idea of potential simultaneous services
3) **Continue contact with clients**
   - Booster and refresher sessions, alumni groups
4) **Involve family members**
   - Source of support to protect against transition set-backs
5) **Hold graduation ceremonies**
   - Important for both graduating client and current client

Challenges in Continuity of Care



N=55
Source: CSC Program Survey (Neylon, 2020)

Disengagement

- "Unplanned" discharge vs. planned discharge
- Different definitions
- Recent review: 12% - 53% (Mascayano et al, Nov 25th)
- An emerging area of study in the U.S.
  - Washington: 12% drop-out rate at one year
  - OnTrackNY: 32% before one year
  - EPICENTER: About 1/3 before first appointment
  - Virginia: About 1/3 ended prematurely within first year
  - Yale STEP: 49% no contact for 3 months or longer
- Outside scope of study but linked to continuity of care

About a third of clients in U.S. drop out?

Wrap Up

Summary

- Programs differ in their philosophy about the underlying purpose of a CSC program, and this relates to decisions around continuity of care.
- The majority of respondents favored a longer program length or length determined by need, and this was true among both sites that do and do not already have this option.
- There are likely to be a subset of clients in any program who, in spite of early intervention, do not progress to the point that a reduction in services is feasible.
- Step-down models are motivated by a similar desire to provide continuity of care, but vary across multiple dimensions.
- Post-transition services that focus on transition-aged youth are highly valued but not widely available.

Summary

- To date, most CSC programs fund continuity of care services through a similar mechanism as their full CSC services, and therefore navigate similar constraints.
- Regardless of the post-CSC placement, CSC programs tend to use similar practices to prepare clients for transition and facilitate continuity of care.
- Lack of community-based options is both a major driver in the development of post-CSC services and a significant barrier in continuity of care.
- Early discharge from CSC programs is a significant issue, but little is currently known about this topic in the U.S.

Policy Implications

① Limited routine community care options

The most-commonly cited challenge for continuity of care

- Direct resources toward development and implementation of evidence-based practices
- Increase state-directed training opportunities
- Improve state-level data collection on transitions
  - Who leaves when, and where do they go?

Policy Implications

② Limited financing options

- Medicaid

  Central to continuity of care for all the case study sites

  - Higher rates to programs that train in EBPs and score high on fidelity
  - Potential of waivers
  - Support of bundled/case-rate approaches

- MHBG funds

  Critical not only to CSC programs, but to continuity of care services, e.g., ETCH, EPIC-NOLA, PEACE, Deschutes EASA

Policy Implications

③ Increased integration

- Linkages with CCBHCs
- Integration with TAY and ACT-TAY programs

④ Telehealth

Active at all sites and overall positive

- Possible because of waivers
- A response to the challenge of transportation – very high potential for future post-transition support
- Limitations to using telehealth for CSC care

Directions for Future Research

1. Where are clients served following discharge from a CSC program and how does placement vary by client characteristics?
2. How do clients fare following discharge from a CSC program?
3. What services are provided to clients who need more intensive, longer term care?
4. To what extent does disengagement occur in CSC programs, and how do teams address this issue?
5. What funding mechanisms can be used to enhance continuity of care?
6. How does integration of first episode psychosis programs within CCBHCs affect a) services for young adults with psychosis and b) continuity of care?
7. How can telehealth support post-CSC care, and what are potential limitations or challenges that must be overcome?
8. How do CSC programs in rural areas address continuity of care?

Study Limitations

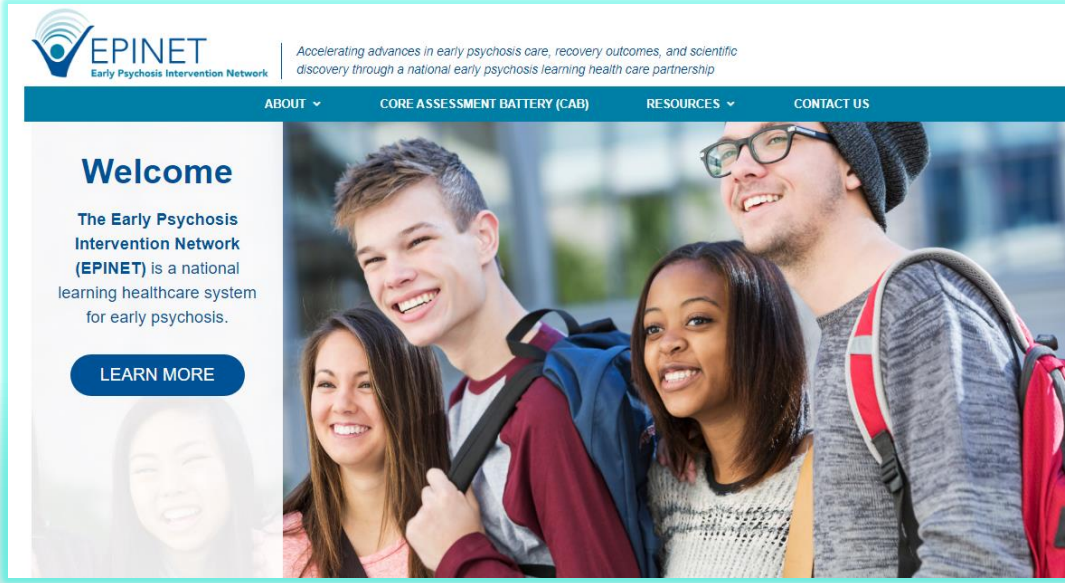
- Case study approach
  - Should not be used to make generalizations
  - Other programs may also be doing interesting things
- Focus on continuity of care for *planned* discharges only
- All data collection was done remotely

EARLY PSYCHOSIS INTERVENTION NETWORK (EPINET)

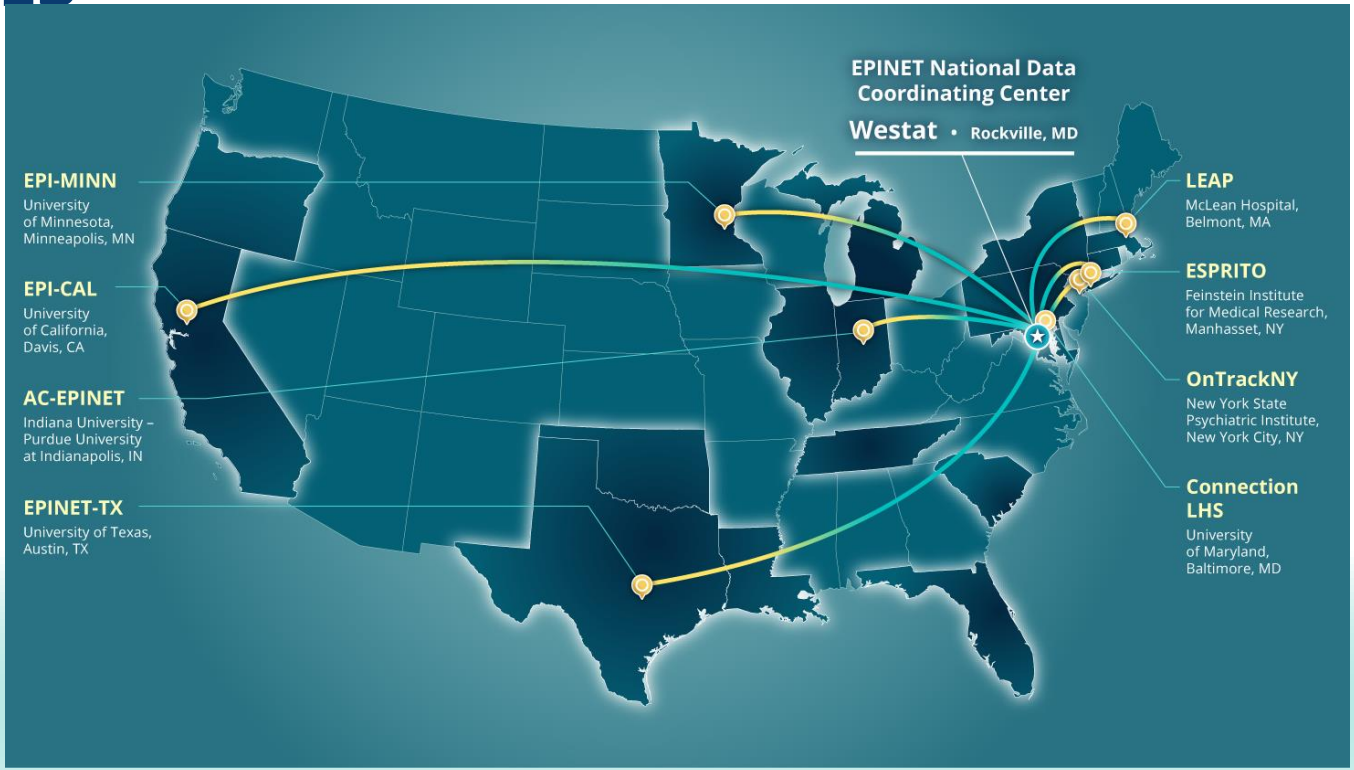
Established through the National Institute of Mental Health in 2019

EPINET links CSC clinics through standard measures and participant-level data collection.

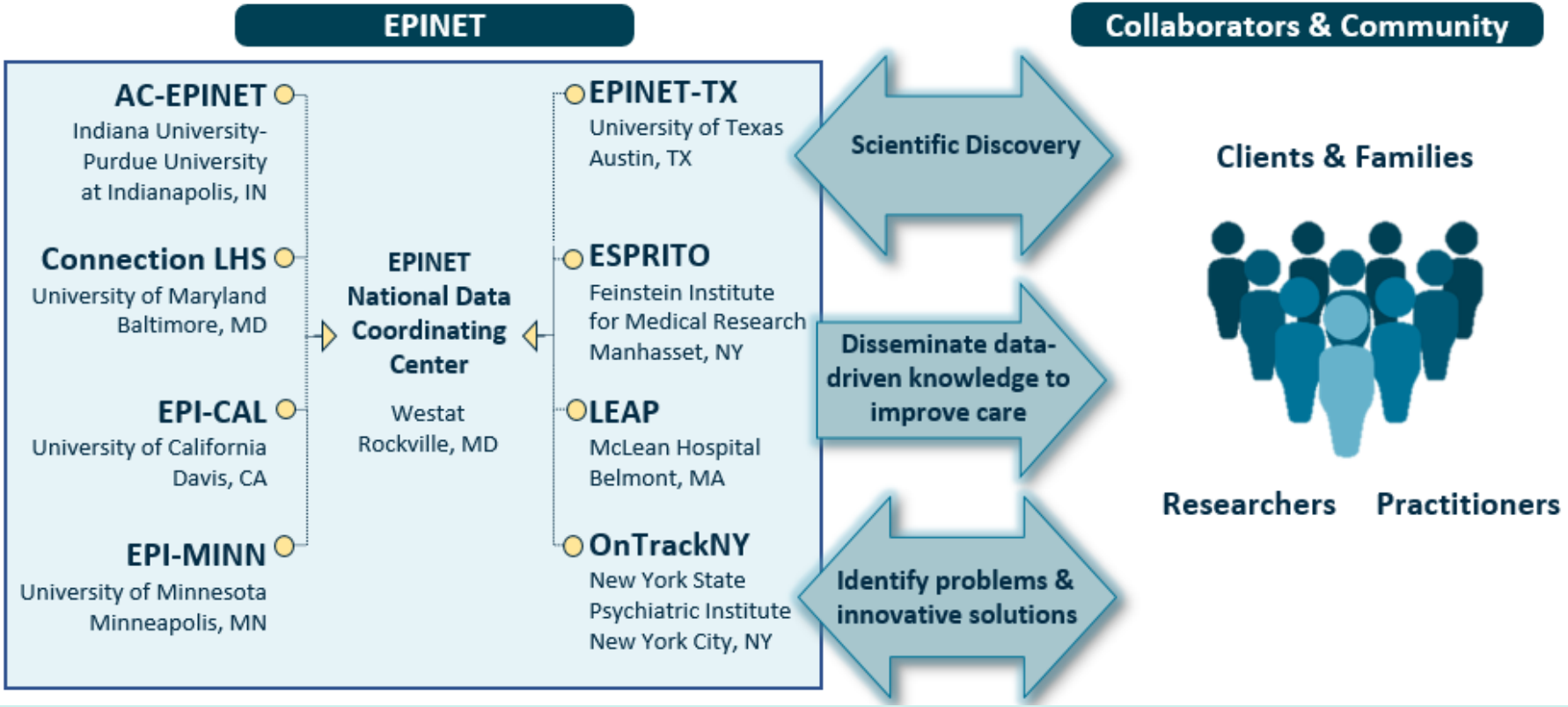
https://NationalEPINET.org



EPINET INCLUDES A DATA COORDINATING CENTER, 8 HUBS, 101 CSC CLINICS ACROSS 17 STATES



A NATIONAL LEARNING HEALTH CARE SYSTEM FOR EARLY PSYCHOSIS

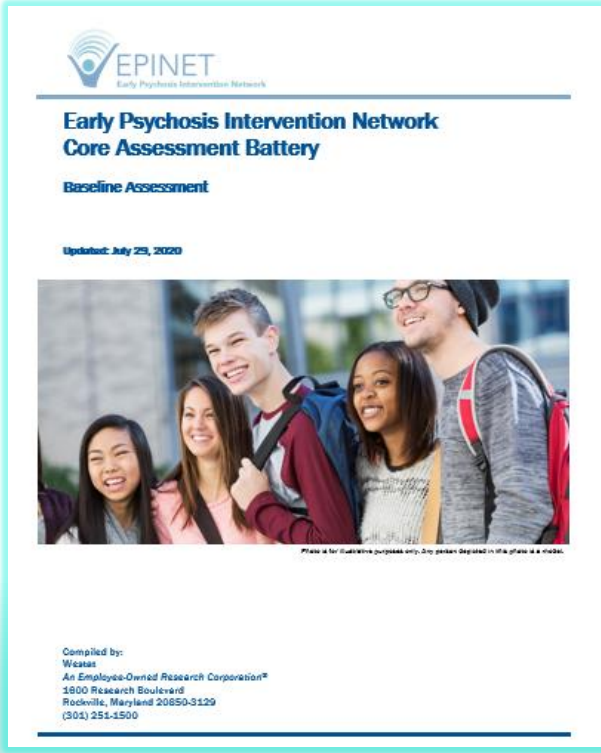


Based on Institute of Medicine (2013). *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington, DC: The National Academies Press.

THE CAB SERVES AS THE BASIS FOR COMMON DATA COLLECTION ACROSS ALL EPINET CLINICS

The CAB was designed as a resource that can reasonably be included in data collection efforts within community-based CSC clinics.

CAB data will be consolidated in a central database with statistical power to answer important research questions.


EPINET
Early Psychosis Intervention Network

Early Psychosis Intervention Network
Core Assessment Battery

Baseline Assessment

Updated: July 29, 2020

Compiled by:
Westat
An Employee-Owned Research Corporation®
1600 Research Boulevard
Rockville, Maryland 20850-3129
(301) 251-1500

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DOMAINS IN THE CORE ASSESSMENT BATTERY

	CAB Domain
1	Cognition
2	Demographics & Background
3	Diagnosis
4	Discharge Planning & Disposition
5	DUP & Pathway to Care
6	Education
7	Employment
8	Family Involvement
9	Functioning
10	Health
11	Hospitalizations

	CAB Domain
12	Legal Involvement
13	Medication Side Effects & Treatment Adherence
14	Medications
15	Recovery
16	Service Use
17	Shared Decision Making
18	Stress, Trauma & Adverse Childhood Events
19	Substance Use
20	Suicidality
21	Symptoms

STANDARDIZED MEASURES IN THE CAB

Domain	Measures	
Cognition	• Brief Assessment of Cognition (BAC-APP v2.1.0)	• Penn Computerized Neurocognitive Battery (PennCNB)
Functioning	• Global Functioning Scale: Social rating (GF Social) • Global Functioning Scale: Role rating (GF Role)	• MIRECC-GAF Occupational rating • MIRECC-GAF Social rating
Medication Side Effects & Treatment Adherence	• Brief Adherence Rating Scale (BARS) • Adherence Estimator	• Intent to Attend and Complete
Recovery	• Questionnaire about the Process of Recovery (QPR)	
Shared Decision Making	• CollaboRATE	
Stress, Trauma & Adverse Childhood Events	• Adverse Childhood Experiences (ACES) • Child and Adolescent Trauma Screen (CATS) Life Events Checklist (LEC)	• Post Traumatic Stress Disorder Checklist for DSM-5
Symptoms	• Modified Colorado Symptom Index • Brief Psychiatric Rating Scale (BPRS)	• Positive and Negative Symptoms of Schizophrenia Scale (PANSS-6)
		• COMPASS 10-item version

BROAD AVAILABILITY OF THE CAB

National EPINET Website

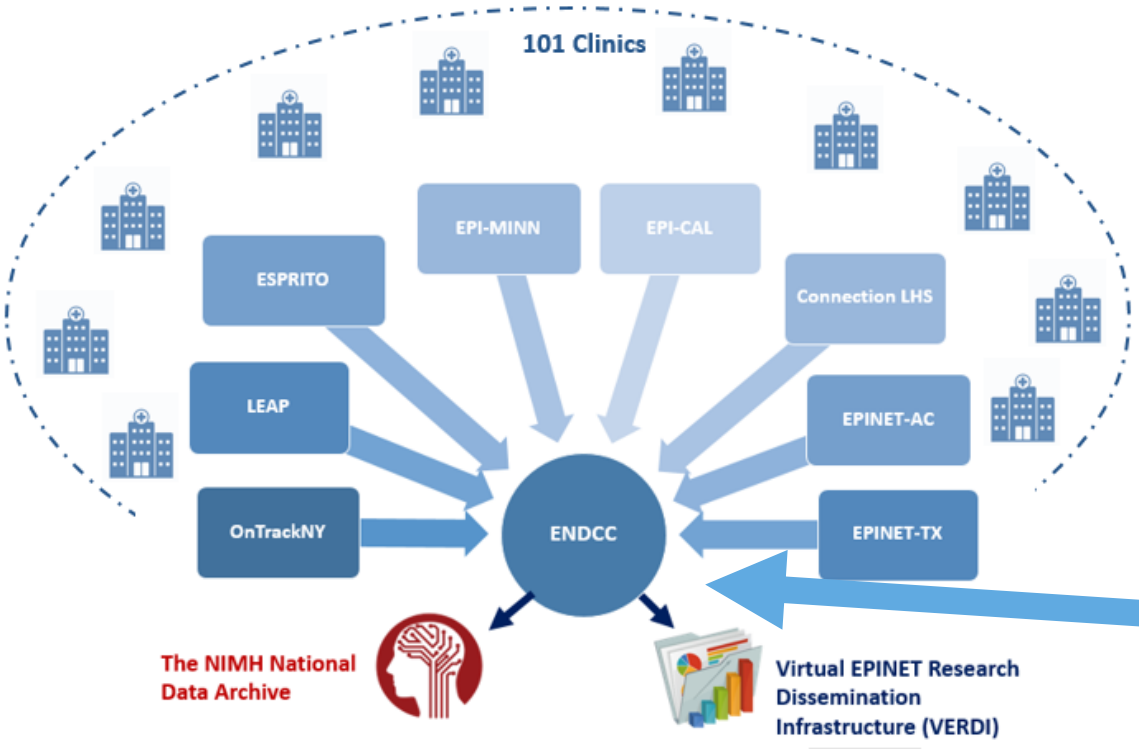
https://nationalepinet.org/core-assessment-battery-cab/

Download the full CAB and User's Guide

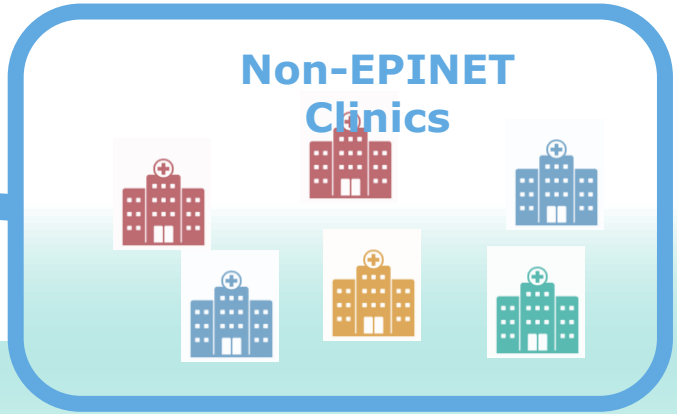
or

Download individual items and measures by domain

Summer 2021



Non-EPINET clinics will be able to contribute client data to EPINET.



BENEFITS OF CONTRIBUTING DATA THROUGH THE WEB-BASED CAB

- Data will be consolidated with the national EPINET database of 101 clinics
- Clinics contributing data will have access to:
  - ✓ Training regarding best practices for administering CAB measures
  - ✓ Training on how to use and interpret client scores on CAB measures
  - ✓ Secure portal to download their own clinic data which can be used for client monitoring and quality assurance

Over time as the EPINET database grows, clinics can:

- ✓ Access a dashboard to compare their data to regional and national data being collected by EPINET clinics
- ✓ Access tools to generate infographic and reports based on clinic data

Thank you

...and discussion