REPORT / FIRST EPISODE PSYCHOSIS

AUGUST 31, 2019

Evaluation of First Episode Psychosis Programs
Fiscal Year 2019

Submitted to the Texas Health and Human Services Commission

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ACKNOWLEDGEMENT

This work is funded through a contract with the Health and Human Services Commission. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the Texas Health and Human Services Commission.

Recommended Citation: Lopez, M. A. & Kramer, M. (August, 2019). Evaluation of First Episode Psychosis Programs: 2019 Report. Texas Institute for Excellence in Mental Health, School of Social Work, University of Texas at Austin.

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Background

An estimated 100,000 young people will develop psychosis each year in the United States (Heinssen, Goldstein, & Azrin, 2014). With a significant impact on an individual's educational, vocational, and social functioning, schizophrenia and related psychotic disorders are some of the most debilitating and costly medical conditions (Charlson, Ferrari, & Santomauro, 2016; Salomon, Haagsma, Davis, et al., 2013). In the last decade, research has shown that reducing the time between the onset of psychosis and access to comprehensive treatment programs can improve outcomes and reduce the long-term disability associated with psychosis (Bird, Premkumar, Kendall, et al., 2010; Penn, Waldheter, Perkins, et al., 2005; Marshall, Lewis, Lockwood, et al., 2005). Effective interventions shown to reduce or prevent the negative sequelae of psychosis generally use a team-based approach, known as Coordinated Specialty Care (CSC), that includes low-dose atypical antipsychotic medication, cognitive behavioral therapy, family psychoeducation, educational and vocational support, and case management (Heinssen, et al., 2014; Mueser & Cook, 2014). In 2009, the National Institute for Mental Health (NIMH) initiated the Recovery after Initial Schizophrenia Episode (RAISE) research program with two similar, but independently developed, CSC programs in the U.S. This research demonstrated that participants in CSC programs had better outcomes than community care (Kane, Robinson, & Schooler, 2016) and that the model could be effectively implemented within community-based programs (Dixon, Goldman, Bennett, 2016).

The Texas Health and Human Services Commission (HHSC) has supported the implementation of first episode psychosis (FEP) programs in ten regions of the state, with additional programs launching in 2019. HHSC has contracted with investigators from the Texas Institute for Excellence in Mental Health (TIEMH) at the University of Texas at Austin to conduct a multi-year, independent evaluation of the effectiveness of FEP programs as implemented in mental health agencies across the state. Each of the current FEP programs in Texas has adopted the same model for intervention, the OnTrackNY model, which is a specific instantiation of the Recovery After an Initial Schizophrenia Episode (RA1SE) Connection Program. In fiscal year 2017, TIEMH investigators conducted a preliminary evaluation of the effectiveness of the program through qualitative interviews with providers and an initial empirical view of trajectories of clinical symptomatology in FEP participants vs. treatment-as-usual groups. Provider reports regarding the success of implementation of the program and clinical outcomes of their clients were uniformly positive. Focusing primarily on clinical symptomatology, empirical results were suggestive of more rapid stabilization and less evidence of worsening of symptoms of psychosis and other broadband domains of symptomatology in FEP participants than in the control groups (Kramer & Lopez, 2017). The empirical findings were preliminary, however, in that the analyses relied only on existing measurement tools, the Child and Adolescent Needs and Strengths (CANS) and Adult Needs and Strengths Assessment (ANSA), which did not allow for a more targeted examination of key symptom domains (e.g., positive and negative symptoms).

The current report provides an update on the status of a more comprehensive evaluation protocol and efforts toward collection of data across sites. The report summarizes an evaluation of fidelity to the CSC model across the participating FEP programs. In addition, the report highlights initial information on a sample of participants enrolled in the program, focusing on recovery-oriented measures in addition to symptomatology and functional outcomes. Characteristics of the program participants are described from both provider and participant perspectives. While preliminary in nature, the report suggests potentially positive responses to treatment in multiple outcome domains.

Methodology

Protocol Development

The evaluation protocol for the FEP program was developed through a participatory research approach. In the initial year of the evaluation, evaluators conducted qualitative interviews with providers across the state to identify key outcomes that were believed to best reflect the goals of the CSC program. Team members also identified any standardized measures that were currently in use within the program. TIEMH utilized this feedback in planning, as well as a review of core measures identified by the National Institute for Mental Health as best practices for FEP programs. After identification of the potential measures, TIEMH held two conference calls with representatives of HHSC and Team Leads/Program Managers across FEP sites to elicit feedback regarding the selection of specific tools and the breadth of outcome domains targeted in the protocol. Following these meetings, TIEMH investigators developed a protocol of instruments and a data collection plan regarding how often specific self-report, clinician-report, and investigator-rated tools would be administered. This protocol was reviewed by HHSC, modified, and approved.

Methods

The FEP evaluation protocol includes a comprehensive battery of intake and outcome assessments to be administered over the course of care. The battery includes self-report scales administered to participants in the FEP program and nominated family members/caregivers, clinician-rated scales, and one investigator-rated scale. Self-report scales are administered to FEP participants at study enrollment, 6 months, 12 months, and at either 18 months or discharge from the program, whichever occurs first. Clinicians complete enrollment and discharge forms, and brief monthly assessments. Data is primarily collected through online surveys, utilizing tablets provided by TIEMH staff.

Inclusion in the research study only requires that a participant is enrolled in the FEP program. Enrollment in the program does include inclusion/exclusion criteria, however, including age of 15 to 30 years, diagnosis of schizophrenia or mood disorder with psychosis, and duration of psychosis of less than two years at program entry (based on date of diagnosis). As this is a naturalistic evaluation of program outcomes, no exclusion criteria have been implemented. Family members of participating patients will be included if they have been identified as a supportive caregiver (e.g., family or close friend) by the participant and consent for contact has been provided.

Program fidelity is measured through the completion of a fidelity rating scale by the evaluation team. Evaluators gather information to complete the fidelity tool during a site visit. The site visits consist of interviews with the FEP team leads, treatment providers, program participants, and family members. The site visits also include an observation of team staffing meetings and reviews of samples of treatment records. When one organization operates two CSC teams, the evaluation team strives to complete two fidelity reviews, although exceptions may occur based on organizational preference and shared staffing.

Evaluation Measures

The following tools or measures are used in the Texas FEP Evaluation protocol:

OnTrackNY Fidelity Assessment Scale (FAS). A 100-item scale designed to assess the fidelity of a specific program to the components of the OnTrackNY training model. The instrument measures each element on 3-point scale, from “unacceptable,” “acceptable,” and “exceptional.” An external evaluator completes the fidelity assessment every two years.

FEP Enrollment Form. This form collects basic demographic information and an estimate of the duration of untreated psychosis. Providers complete this form at entry to the program.

Discharge Form. This form collects basic information about participant status at discharge and reason for discharge from the program.

Event Tracking. The event tracking form gathers information on both positive and negative events or status changes that could influence trajectory of progress through the program. Providers complete the form each month based on information shared at team meetings.

Positive Symptom Rating Scale (PSRS) version 5.0. This four-item rating scale for the positive symptoms of psychosis was developed for use in Texas based on the Brief Psychiatric Rating Scale. Items ratings range from not present (1) to extremely severe (7). A mental health provider completes this instrument every six months.

Brief Negative Symptom Assessment (BNSA) version 5.0. This four-item rating scale for the negative symptoms of psychosis was created for use in Texas and adapted from the Negative Symptom Assessment and the Scale for the Assessment of Negative Symptoms. Items are rated by clinicians from 1 to 6, ranging from “normal” to “severe.” A mental health provider completes this instrument every six months.

Alcohol Use Scale (AUS). A mental health provider completes this single-item scale rating alcohol use, abuse, and dependence. The instrument is collected monthly.

Drug Use Scale (DUS). A mental health provider completes this single-item scale rating drug use, abuse, and dependence. The instrument is collected monthly.

World Health Organization Disability Assessment Schedule 2.0 (WHO DAS 2.0). The WHO DAS is 36-item measure to assess health and disability in six domains of functioning: cognition, mobility, self-care, getting along, life activities, and participation. This self-report measure will be collected every six months.

Patient Health Questionnaire (PHQ-9). The PHQ-9 assesses diagnostic symptoms of depression. The instruments total score ranges from 0 to 27, with mild symptoms at scores of 5 to 9, moderate symptoms from 10 to 14, moderately severe symptoms from 15 to 19, and severe symptoms from 20 to 27. Participants complete the PHQ9 every six months.

Generalized Anxiety Disorder (GAD-7). The GAD-7 is a brief self-report measure of anxiety symptoms. Responses on items reflect “not at all” as a score of 0 to “nearly every day” as a score of 3. Total scores range from 0 to 21, with a range of 5 to 9 reflecting mild symptoms, 10 to 14 reflects moderate symptoms, and 15 to 21 reflects severe symptoms. Participants complete the measure every six months.

Personal Well-being Index (PWI). The PWI is a 7-item scale that measures satisfaction with life in various domains or quality of life. Respondents rate their satisfaction on a scale of 0 to 10, and the total score is converted to a range of 0 to 100, with higher scores reflecting greater quality of life. Participants complete this measure every six months.

Mental Health Confidence Scale (MHCS). The MHCS is a 16-item scale to assess efficacy and confidence in one's ability to cope with issues often related to mental disorders. Items are rated on a six-point scale from 1 "very nonconfident" to 6 "very confident;" therefore, higher scores reflect greater confidence. Participants complete this measure every 6 months.

SCORE-15 Index of Family Functioning and Change. The SCORE-15 measures the quality of family relationships and family disruptions. The three subscales range from 0 to 25 and the total score ranges from 0 to 75, with lower scores reflecting better family functioning. Participants complete the measure every six months.

Burden Assessment Scale (BAS). The BAS is a 19-item scale measuring the impact that the participant's illness has on the family member. Each statement is rated on a 4-point scale, where 1 is "not at all," 2 is "a little,", 3 is "some," and 4 is "a lot." Responses are summed, with higher scores indicating greater levels of caregiver burden. The BAS is completed by a participant-identified family member every six months.

Prospective Evaluation

Update on Progress of Prospective Evaluation

The focus of the year's activities was to refine the data collection tools and processes, continue to recruit CSC teams, provide training to teams on data collection, and finish fidelity site visits. Many of these goals were accomplished, but barriers also impeded the progress on others. The team was successful in completing fidelity site visits with four additional teams. With fidelity information reflecting seven CSC teams, data could be aggregated to provide a benchmark for teams to reflect on their own fidelity measures. Each site participating in the fidelity review was provided a site fidelity report, noting team strengths and areas for improvement. A web-based or in person meeting was held with team members to review the results, answer questions, and discuss recommendations.

As data collection began, the evaluation team noted any difficulties in the data collection tools or opportunities to use the technology to enhance data quality. A number of adjustments were made to the tools to increase clarity or reduce the likelihood of missing or inappropriate data. The team will be working towards developing data quality reports that can aid sites in correcting any remaining data quality issues. Evaluators met with the teams who were actively submitting data to discuss any concerns, answer questions, and request suggestions for changes.

Site recruitment efforts were slow and only minimal progress was made this year. There were a few issues that impeded progress. The evaluators bear some responsibility for not being persistent in ongoing follow-up with team leads. The evaluation study has required some level of approval at each organization, with the process for that approval varying greatly. Frequent follow-up was needed to ensure team leads or other contacts were reminded of the next steps or to check back in on the approval process. For most sites, there was not a clear process for approving a project in which Protected Health Information (PHI) would be shared, but research was not being conducted. Some sites used existing research approval processes, others aimed for a separate Business Associate Agreement, and others approved through their executive leadership. Table 1 provides an update on the status of each site.

Table 1. *Current Status of Site Participation*

Site	Status
The Harris Center	The Harris Center's two CSC teams are engaged in the evaluation. The Harris Center's IRB initially approved the project last year, and reviewed it two additional times this year.
Metrocare Services	The Metrocare Services IRB approved the project. Fidelity data has been collected, but the agency has not yet submitted participant data.
Bluebonnet Trails	Bluebonnet Trails Community Center has participated in a fidelity assessment. The agency has required a BAA to participate in the participant data collection. The BAA has been approved by UT, but approval within the organization has been stalled.
Burke Center	This agency declined to participate initially, but the evaluation team hopes to engage in additional discussions about the benefits.
Texas Panhandle Centers	This agency declined to participate initially, but the evaluation team hopes to engage in additional discussions about the benefits.

Integral Care	Integral Care has participated in the fidelity assessment and approval by the Research Committee was recently received. The staff have started data collection in the last month.
Tropical Texas	Tropical Texas Behavioral health has participated in the fidelity review and is currently engaged in the evaluation.
Center for Health Care	Progress slowed down following some team staffing changes. The team lead submitted information for approval by the management team, but no current approval is in place.
Emergence	Approvals are in place for participation at Emergence and the team is currently engaged in the evaluation.
MHMR of Tarrant County	Participation with MHMR of Tarrant County requires approval by the agency IRB. An IRB application has been submitted and reviewed and modifications are pending.

Site Fidelity to Coordinated Specialty Care

Interpretation of the Fidelity Assessment Scale (FAS). The FAS scale, measuring fidelity to the OnTrackNY coordinated specialty care model, is presented in Appendix A. Each of the 100 items is rated “Unacceptable,” “Acceptable,” or “Exceptional,” which correspond to scores of zero, one, or two, respectively. State median scores across the items on the 23 subscales are presented, with scores ranging from 0 to 2. A rating of “acceptable” reflects a minimum standard for fidelity on the item; therefore, the percentage of items within a subscale rated as“acceptable” is presented. Programs should aim for 100% of items to be within the “acceptable” range. Additionally, the percentage of items within the “exceptional” range are presented, highlighting areas where the programs have exceeded minimum standards for fidelity. A 27-item summary scale was identified by the developers to reflect the most critical components of fidelity and results for this Critical Item scale are also presented. The 23 subscales of the FAS have been clustered into content groups reflecting similar constructs, representing Team Attributes, Enrollment/Discharge, Provision of Services, Team Roles, and Medical Services.

Overall Fidelity. Overall fidelity scores across sites and for each team are presented in Table 2, masked for the site/team name. The median score for the Total of the 100-item FAS across sites was 1.30 (i.e., between “Acceptable” and “Exceptional”), with a range of 1.18 to 1.45. Table 1 also shows the percentage of the 100 items rated at Acceptable levels and above (i.e., ≥ 1.00) and the percentage of items scored Exceptional (i.e., 2.00). Across teams, almost all items (95% of 600 ratings) met OnTrackNY fidelity acceptable standards, and 35% exceeded those standards. The cross-site median Critical Items score was 1.43, with a range of 1.37 to 1.52, 99% of 162 ratings were at acceptable levels and above, and 44% of item ratings were exceptional.

Table 2. *Cross- and Specific-Site Scores on the 100-Item OnTrackNY Fidelity Assessment Scale and Critical Items*

Overall Scores	*Description*	*Items*	*Mean*	*% Acceptable*	*% Exceptional*	*State Median*
Total	Total score of all fidelity items	100		95%	35%	1.30
Team A			1.45	97%	48%	
Team B			1.29	95%	34%	
Team C			1.18	93%	25%	
Team D			1.32	97%	35%	
Team E			1.26	94%	32%	

Team F			1.31	94%	37%	
Critical	Critical fidelity components	27		99%	44%	1.43
Team A			1.48	96%	52%	
Team B			1.37	100%	37%	
Team C			1.41	100%	41%	
Team D			1.44	100%	44%	
Team E			1.52	100%	52%	
Team F			1.37	96%	41%	

Subscale Scores. Cross-site scores on the FAS subscales are presented in Table 3. Ratings across the teams were at the acceptable level or above for all items on 13 of 23 subscales (57%). Items receiving 'Unacceptable' scores were made on ten subscales, ranging from one to 11 ratings for a given subscales' items scored in this manner. Exceptional ratings ranged from zero to 75% across subscales, with a median of 33%.

Table 3. *Cross-Site Scores on the OnTrackNY Fidelity Assessment Subscales*

Subscale	*Description*	*Items*	*Ratings*	*% Acceptable*	*% Exceptional*	*State Median*
Team Attributes						
Staffing	Team appropriately staffed	3	18	100%	0%	1.00
Team Integration	Team communicates, discusses clients	5	30	100%	53%	1.40
Supervision	TL provides supervision	4	24	100%	54%	1.50
Caseload	Appropriate client to staff ratio	3	18	100%	11%	1.00
Enrollment/Discharge						
Eligibility	Documents client fit to the program	5	30	100%	13%	1.20
Outreach	ORC develops contacts, educates	6	36	97%	56%	1.50
Referrals	Timely intake following screening	6	36	97%	44%	1.42
Discharge	Transition plan, follow-up	7	42	95%	14%	1.00
Provision of Services						
Services	Frequency and availability of services	2	12	100%	75%	1.75
Crisis Services	Timely/supportive crisis management	2	12	100%	43%	1.50
Core Sessions	Training/delivery of care processes	3	18	94%	17%	1.00
Safety	Suicide assessment and intervention	4	24	100%	13%	1.00
Family Involvement	Frequency and availability	5	30	90%	33%	1.20
Substance	Assessment and intervention provided	4	24	100%	8%	1.00
Trauma	Assessment and intervention provided	2	12	75%	17%	1.00

Team Roles						
Case Management	PC addresses client concrete needs	2	12	100%	33%	1.25
Psychoeducation	PC uses psychoeducation regularly	2	12	100%	8%	1.00
SEES	Frequency/availability, track status	8	48	98%	29%	1.25
Peer Specialist	Frequency/availability, support	5	30	90%	50%	1.50
CBT/MI	Provided individually and in groups	4	24	83%	46%	1.25
Medical Services						
Medications	Person-centered prescribing practices	8	48	100%	60%	1.56
Metabolic	Regular weight and lab assessments	3	18	100%	56%	1.67
Nurse	Regular visits to the nurse	4	24	54%	33%	0.75

Teams' Strengths. All six teams averaged higher than acceptable ratings overall (i.e., 100-item Total score mean > 1.00), and each team scored more highly on the critical items than the full item set. Average ratings met or exceeded the Acceptable criterion for each item in the domain of Team Attributes. Average ratings were particularly strong (i.e., median ≥ 1.50) for subscale scores of *Supervision*, *Outreach*, *Services*, *Crisis Services*, *Peer Specialist*, *Medications*, and *Metabolic*. Relative strengths (i.e., median > 1.00 and < 1.50) included the *Team Integration*, *Eligibility*, *Referrals*, *Family Involvement*, *Case Management*, *SEES*, and *CBT/MI* subscales.

Areas for Improvement. In terms of areas in which the programs can continue to improve, several subscales showed ratings with lesser proportions of items meeting acceptable or exceptional ratings (i.e., < 90%). The *Nurse*, *Trauma*, and *CBT/MI* subscales showed 54%, 75%, and 83% of item ratings met criteria, respectively. The *Nurse* subscale includes items that measure the access FEP participants have to nursing services in terms of frequency of contact and wellness promotion. The *Trauma* subscale includes items that measure the assessment of post-traumatic stress for program participants and provision of trauma-focused treatment, when aligned with participant preference. The *CBT/MI* subscale includes items related to interventions provided by the primary clinician and in group therapy, with the latter receiving lower ratings for sites not offering groups as part of their programs. Subscales with few exceptional ratings, such as *Substance* and *Psychoeducation* may also be areas for improvement.

Data Reporting

Four sites have been recruited this year to participate and are contributing data to the prospective evaluation. Sites have been included in the data collection at various points during the year, with the variability due to differences in approval processes. Table 4 illustrates the data collection that has occurred to date. Generally, sites have selected to ask participants to complete the full battery of brief instruments, although have been provided an abbreviated battery of core measures if the full battery is not feasible. Some missing data reports are evident, primarily in ensuring that all individuals completing self-reports have a matching enrollment form. The evaluation team's focus on data management issues was not adequate to ensure that sites are able to create workflows that integrate data collection. Over the next year, the team plans to focus on frequent communication with sites regarding data quality and regularly prompt sites to address missing forms. This will be a priority focus area, along with the recruitment of additional program sites.

Table 4. *Current Data Participation in Each Data Tool*

	Enrollment Form	Self-Report Assesments (Full)	Self-Report Assessments (Brief)	Family Assessment	Monthly Reports	Discharge Form
All LMHAs	50	109	13	13	80	5
Harris Center	2	41	4	1	4	1
Tropical Texas	33	52	2	12	42	4
Emergence	13	90	1	0	13	0
Integral Care	0	2	6	0	20	0
Missing	1	2	0	0	1	0

Demographics of Sample

Since the data does not yet reflect the majority of the population served, the results described should be considered a reflection of the data that will be available through the evaluation, rather than a generalizable description of those served. As more data is collected at participating sites, there will be more confidence that the measures fully reflect the individuals served in the program.

Demographic information is presented on all participants with at least one available assesment/form. As some individuals completed self-report instruments but did not have an enrollment form, participants were matched with the state database and demographic information was gathered from administrative sources. The demographic characteristics of individuals served is presented in Table 5. Participants were more likely to be male (55.4%) and Hispanic/Latino (47.5%). Participants were most commonly represented in the 18 to 23 years old age group, with an average age of 20.6 years.

Table 5. *Demographics of Extended Measures Sample*

Characteristic	N	%
Gender		
Male	56	55.4%
Female	35	34.7%
Missing	10	9.9%
Race/Ethnicity		
Hispanic/Latino	48	47.5%
Black/African American	17	16.8%
White/Caucasian	24	23.8%
Asian	1	1.0%
Native American	0	0%
More than One Race	1	1.0%
Missing	10	9.9%
Age on Sept. 1, 2018		
15-17	11	10.9%
18-20	32	31.7%
21-23	23	22.8%

24-26	13	12.9%
27-29	9	8.9%
30-32	3	3.0%
Mean age at admission	M=20.6	SD=3.7

As noted above, a subset of the participants had a completed enrollment form (*n*=50), which includes additional information about the young person at entry to the program. Table 6 provides a summary of other information reflected at enrollment. A similar distribution of participants had not completed high school (38.8%) or had a high school degree (36.7%). Only one participant had a GED. One-fifth of the participants had completed some college coursework, with only one having graduated from college at entry. Forty percent of the participant were enrolled full time in school at program entry. This demonstrates the potential importance of educational supports, if further education or training is a goal of the participant.

At program entry, only 6% of the sample was employed. An additional 36.2% were unemployed, but interested in employment. Of the 55.3% of participants who were unemployed and not interested, only 57.7% were enrolled in school, suggesting that additional participants could be engaged in education or employment goals. Almost all participants were in stable housing at program entry, with the vast majority living with family or spouse. One participant was considered homeless at entry. An additional measure of interest was whether the participant had a primary care provider for medical care. Results suggested that many individuals (61.2%) did not have a primary care provider at program entry. Others were either engaged with a provider integrated into the behavioral health home (10.2%) or external to the organization (28.6%).

The most common referral sources for the program were behavioral health providers (including within the organization), the hospital or emergency room, or self-referral. The majority of participants (72.9%) had experienced at least one psychiatric hospitalization prior to enrollment. Since Coordinated Specialty Care aims to reduce the time from initial onset of psychosis symptoms to access to effective treatment, measures of the duration of untreated psychosis are important. However, initial dates of psychosis symptoms and treatment pathways can be challenging to measure. Providers reported 60.9% of the participants had psychosis symptoms begin on the same day as their first treatment for psychosis, likely reflecting when they were first diagnosed, rather than when symptoms began. Other responses varied from three days to 192 days. Since the first treatment for psychosis may not have been through the CSC program, the duration between initial treatment and CSC enrollment was also examined. For those whose CSC enrollment was after their initial treatment (> 0 days), it took a median of 173 days to achieve access to the specialty program. Communities should monitor this benchmark to examine if greater education, outreach, or expanded capacity reduces this length of time.

Table 6. Baseline Characteristics of Extended Sample

Characteristic	**N** (n=50)	**%**
Highest Level of Education Completed		
Some High School	19	38.8%
Graduate Equivalent Degree (GED)	1	2.0%
High School Degree	18	36.7%
Vocational Degree	0	0%
Some College	10	20.4%
Associate Degree	0	0%
College Degree	1	2.0%
Missing	1	-

Referral Source		
Self	10	21.3%
Family Member	0	0%
Friend or Significant Other	0	0%
Teacher or School	0	0%
Behavioral Health Provider	24	51.1%
Hospital or ER	12	25.5%
Law Enforcement	0	0%
Other	1	2.1%
Missing	3	-
Family Involvement Preference		
Prefers no involvement	8	16.3%
Prefers involvement with restrictions	5	10.2%
Prefers involvement with no restrictions	36	73.5%
Missing	1	-
History of Psychiatric Hospitalization		
Never Hospitalized	13	27.1%
Hospitalized Once	21	43.8%
Hospitalized More than Once	13	29.2%
Missing	2	-
Educational Status		
Not Enrolled in School	28	59.6%
Enrolled Part-time in School	0	0%
Enrolled Full-time in School	19	40.4%
Employment Status		
Not Employed, Not Looking	26	55.3%
Not employed, interested in employment	17	36.2%
Engaged in unpaid internship	0	0%
Employed, part-time	3	6.4%
Employed, full time	0	0%
Other	1	2.1%
Missing	3	-
Living Situation		
Housed with family, spouse, or parents	45	95.7%
Housed with unrelated roommates	1	2.1%
Housed living along	0	0%
Shelter or transitional living	0	0%
Homeless	1	2.1%
Missing	3	-
Primary Care Health Home		
Engaged with external provider	14	28.6%
Engaged with integrated provider	5	10.2%
No primary care provider	30	61.2%
Missing	1	-

Symptomatology and Functioning

Psychiatric symptomatology and functioning was measured across a variety of domains, through both provider and client report. Initial scores of positive psychosis symptoms indicated about 20% of the sample fell in the moderate level of severity and 3.7% fell in the severe level (see Table 7). Scores on negative symptoms showed similar proportions. The highest positive symptom severity scores were reported for Suspiciousness (*m*=3.67, *sd*=1.47) and Hallucinations (*m*=3.33, *sd*=1.59), with the average scores falling between “mild” and “moderate” severity. The highest negative symptom score was Reduced Social Drive (*m*=4.12, *sd*=1.53), with the average score falling between “moderate” and “marked” severity. Self-report measures of depression and anxiety demonstrated both were common, with between 12% and 13% reporting severe levels of symptoms. Providers indicated that alcohol abuse or dependence was not a concern for the participants; however, drug abuse or dependence was reported in one-fifth of the population. These findings underscore the comorbid presentation of participants in the CSC program, with anxiety, depression, and drug use (primarily marijuana) key issues to address.

Functioning is measured across a variety of domains, with means ranging from 0 (no impairment) to 1 (extreme/cannot do). Participants reported some level of functional impairment across all of the domains. The greatest level of impairment was seen on Participation in Society, which measures negative impacts on engagement in community, negative attitudes of others, and negative impacts on emotions, financial stability, and family problems. More impairment was also seen on the Relations scale, measuring interpersonal functioning, and Cognition, measuring capacities such as memory, attention, understanding, learning, and problem solving. Average ratings on individual items on the WHO DAS are presented in Appendix B.

Table 7. *Measures of Symptom Severity and Functioning – First Available Measure*

Characteristic	**M**	**SD**	**Range**	**% Elevated**
Symptomatology				
Negative symptoms of psychosis (BNSA; n=25)	2.75	0.91	1.0 – 5.0	20.0% Moderate 4% Severe
Positive symptoms of psychosis (PSRS; n=27)	2.88	1.05	1.0 – 5.75	18.5% Moderate 3.7% Severe
Depression (PHQ-9; n=61)	9.49	7.13	0 – 27.0	27.9% Moderate 4.9% Moderately Severe 11.5% Severe
Anxiety (GAD; n=54)	8.04	6.00	0 – 21.0	18.5% Moderate 13.0% Severe
Alcohol use (AUS; n=15)	1.13	0.35	1 – 2.0	0% Abuse or Dependence
Drug use (DUS; n=15)	1.67	1.29	1 – 6.0	20% Abuse or Dependence
Functioning				
WHO DAS Cognition (n=62)	0.339	0.235	0 – 1.0	21.0% Moderate 3.2% Severe
WHO DAS Mobility (n=62)	0.219	0.212	0 – 1.0	11.3% Moderate 1.6% Severe
WHO DAS Self Care (n=62)	0.211	0.228	0 – 1.0	3.2% Moderate 6.5% Severe
WHO DAS Relations (n=62)	0.348	0.271	0 – 1.0	21.0% Moderate

				11.3% Severe
WHO DAS Household (n=62)	0.293	0.284	0 – 1.0	12.9% Moderate 14.5% Severe
WHO DAS Work/School (n=47)	0.297	0.284	0 – 1.0	21.3% Moderate 8.5% Severe
WHO DAS Participation (n=61)	0.382	0.245	0 – 1.0	18.0% Moderate 11.5% Severe

Strengths and Recovery

While reductions in symptoms and increased functioning can be an important goal, ultimately participants are seeking improvements in quality of life and a sense of empowerment to manage their mental health in the future. Initial results on the personal well-being index suggest that many individuals fall below the western normative mean of 70 to 80. In the current sample, only 37.7% report well-being at or above this normative range. Mental health confidence, or an individual’s belief that he or she can overcome their current challenges, is a critical component of recovery. Initial scores on the Mental Health Confidence Scale suggest that particpants report confidence averaging between “slightly confident” and “confident” with the highest ratings on Advocacy and the lowest rating on ability for Coping.

Table 8. *Measures of Strengths and Recovery*

Characteristic	**M**	**SD**	**Possible Range**	**% Elevated**
Quality of Life				
Personal Well-being Index (n=60)	56.65	25.97	0 - 100	37.7% Average or Greater
Empowerment (MH Confidence Scale)				
Optimism Scale (n=54)	26.06	7.45	6.0 – 36.0	Cut-offs not published; Higher score is > confidence
Coping Scale (n=53)	28.57	7.74	7.0 – 42.0	Cut-offs not published; Higher score is > confidence
Advocacy Scale (n=53)	14.51	3.52	3.0 – 18.0	Cut-offs not published; Higher score is > confidence
Total Confidence Scale (n=54)	67.72	17.22	16.0 – 96.0	Cut-offs not published; Higher score is > confidence

Family

For the youth and young adults experiencing symptoms of psychosis, strong relationships with supportive family members can be an important protective factor. Results on family scales are presented in Table 9. On the Score-15 measure of family functioning, lower scores reflect better family functioning. Average scores on the Strengths and Adaptability scale indicate that participants felt positive statements regarding family trust, communication, and adaptablity “describe us well”. Average scores also indicated that statement about families being overwhelmed by difficulties and crises and blaming each other when things go wrong described them “partly” to “well.”

Respondents reported fewer issues with poor family communication, such as lying, expressions of anger, or an inabilty to disagree. Overall scores reflect some disruptions in family functioning similar to or greater than those seeking family therapy, with developers reporting an average of 39 for clinical samples and 26 for normal samples. This is primarily due to the sense that families are overwhelmed by their current challenges.

The sample of caregivers who completed the family Burden Assessment Scale is quite small. Scores range from 1 to 4, with lower scores reflecting less perceived burden. Mean scores suggest family caregivers experience the most burden related to worry and guilt about their contribution or response to their loved one's illness, with average scores between "a little" and "some." Families reported the least burden related to friction with family members and others or the experience of stigma, with respondents' average scores between "not at all" and "a little."

Table 9. *Measures of Family Functioning*

Characteristic	**M**	**SD**	**Range**	**% Elevated**
Family Functioning (SCORE-15)				
Strengths & Adaptability (n=54)	12.80	4.83	5.0 – 25.0	50% Strength
Overwhelmed by Difficulties (n=54)	18.44	5.13	5.0 – 25.0	7.4% Strength
Disrupted Communication (n=54)	13.04	5.34	5.0 – 25.0	46.3% Strength
SCORE-15 Total (n=54)	44.28	7.21	15.0 – 75.0	13.0% Strength
Family Burden (BAS)				
Activity Limitations (n=11)	2.19	0.75	1.0 – 4.0	Cut-offs not published; Lower score is < burden
Feelings of Worry and Guilt (n=11)	2.55	0.77	1.0 – 4.0	Cut-offs not published; Lower score is < burden
Social Strain (n=10)	1.68	0.67	1.0 – 4.0	Cut-offs not published; Lower score is < burden
Total Perceived Burden (n=11)	2.14	0.63	1.0 – 4.0	Cut-offs not published; Lower score is < burden

Initial Examination of Changes over Time

Important Events. Critical events are reported monthly for participants. This includes positive events, like obatining a primary care provider or getting hired for a new job, as well as less positive events, like psychiatric hospitalization. There are a few challenges with this data presently, which limit their usefulness as outcome measures. First, only 43 out of the 80 individuals with monthly reports have an enrollment form. Many status changes are not easy to interpret without information about the status at program entry. Second, many participants have a limited number of months in the dataset. Therefore, the data will be used to describe initial trends but not to examine participant outcomes in care.

Eighteen of the 80 participants (23.5%) with monthly reports had at least one psychiatric hospitalization during the tracking period. A smaller proportion (13.75%) had at least one emergency room visit. Providers were aware of seven individuals (8.75%) who attempted suicide during the reporting period. Three of the 27 participants (11.1%) who were not enrolled in school at program entry later became enrolled in an educational setting. Eight of the 40 participants (20.0%) who were unemployed at entry to the program later gained employment. More than half of the 29 participants who lacked a primary care provider at program entry (n=17, 58.6%) later gained access to a physician.

Outcomes. At present, most participants only have one time point reflected in the evaluation; therefore any examination of changes over time is limited. However, a preliminary examination was conducted to identify any trends in the symptom, functioning, and select recovery measures. These preliminary analyses should not be considered definitive indicators of positive or negative results, as the sample size remains small at present and may not be representative of the sample as more data is collected. Additionally, those participants who have two data points have had a limited time in treatment, with only six months between the initial and subsequent data points (*m*=192.5; *sd*=47.0). Results of these preliminary explorations are presented in Table 10.

In all analyses, follow-up assessments suggested improvement over time, either through reductions in negative outcomes or improvements in positive ones. Five of the ten analyses demonstrated a statistically significant change. Participant reports of depression and anxiety both reflected a significant descrease in symptoms over time, with reductions of 35.7% and 56.6% of initial scores respectively. Statistically significant improvements in participant functioning were reported for mobility, relations with others, and participation in society. Changes reflected a 39.3% improvement in mobility, a 28.8% improvement in relations, and a 44.8% improvement in societal participation. While preliminary in nature, the findings suggest the possibility of improvement across multiple domains over time.

Table 10. *Changes in Self-Report Outcomes over Time*

	Initial Mean	**Follow-up Mean**	**Difference**	**Statistic**	**Significance**
Symptoms: Depression (n=23)	8.52	5.48	3.04	t=2.08	*p*=0.05**
Symptoms: Anxiety (n=23)	7.26	4.11	3.16	t=2.80	*p*=0.01***
Functioning: Cognition (n=24)	0.330	0.293	0.036	t=0.87	*p*=0.40
Functioning: Mobility (n=24)	0.196	0.119	0.077	t=2.08	*p*=0.05**
Functioning: Self Care (n=24)	0.182	0.109	0.073	t=1.74	*p*=0.09*
Functioning: Household (n=24)	0.273	0.193	0.081	t=1.49	*p*=0.15
Functioing: School / Work (n=6)	-	-	-	-	-
Functioning: Relations (n=24)	0.208	0.148	0.060	t=2.19	*p*=0.04**
Functioning: Participation in Society (n=24)	0.328	0.181	0.147	t=3.27	*p*=0.003***
Positive Well-being (n=22)	61.95	68.05	-6.10	t=-1.66	*p*=0.11
Mental Health Confidence (n=19)	66.63	72.53	-5.89	t=-1.96	*p*=0.07*

Significance indicators: **p* ≤ .10; ***p* ≤ .05; ****p* ≤ .01

Summary and Next Steps

Evaluation Summary

The state evaluation of FEP programs continued to make progress. Key accomplishments were the completion of fidelity assessments with eight FEP teams (one combined across two teams), the training of four communities in the evaluation protocol, and initiation of data collection at these sites. Additional progress was also made recruiting sites and advancing through local approval processes. This has been a time and resource intensive process, but several additional sites should be ready to engage in the near future. The evaluation team also met with sites to provide feedback on the fidelity assessment and debrief on any challenges providers are having with data collection. As a result of these conversations and initial reviews of data quality, several changes were made to data collection tools to improve data quality.

The initial analysis of available data provides some important information regarding the participants served in the CSC program. Key findings are:

- Most participants were referred to services through a behavioral health provider or hospital/emergency room. Referrals from schools, the legal system, family and friends were uncommon, suggesting possible avenues for additonal education and outreach.
- The majority of participants were not connected with a primary care provider at program entry, suggesting a need for coordination to support participants in establishing a health home.
- A large minority of participants were enrolled in school at program entry; however, very few were currently employed.
- Participants demonstrated multiple comborbidities, with many describing challenges with depression, anxiety, positive and negative symptoms of psychosis, and a variety of functional impairments.
- The most common areas of difficulty reported by clinicians and participants centered around motivation for engagement with others, maintenance and development of relationships, and participation in community.
- Most participants have not achieved their optimal quality of life and report low levels of confidence in their ability to manage their mental health challenges and advocate for their needs.
- Participants report some disruptions in family functioning, particularly in the sense that family members are overwhelmed by crises and other concerns.
- Initial examination of changes in evaluation measures over time are promising, suggesting both reductions in symptomatology and improvements in functioning.

Next Steps

1. TIEMH will develop site reports to provide feedback on data quality and process and outcome measures. When available, TIEMH will provide sites with communication tools that highlight local evaluation findings.
2. TIEMH will continue to engage additional sites through approval processes and follow-up. TIEMH aims to add four to six more sites in the evaluation during the next year.
3. TIEMH will provide outreach to new FEP sites to provide information about the evaluation and begin discussion of approval processes.

4. As additonal data is collected and sample sizes increase, TIEMH evaluators will collaborate with HHSC and local stakeholders to identify key evaluation questions that will further the programs’ effectiveness and reach.

Appendix A

The 100-Item OnTrackNY Fidelity Assessment Scale Identifying Critical (Italicized) and Subscale Item Sets

Team Attributes

Staffing

1. No less than 4.0 FTE; 4.0 FTE total; each team is staffed with persons meeting at least the minimum credentialing requirements and are fulfilling the following (TL, PC, ORC, SEES, Prescriber, Nurse, and Peer Specialist).
2. Vacancies do not exceed 30.
3. When meeting with the team determine that there is a TL, ORC, SEES, Peer Specialist, Prescriber, and Nurse.

Team Integration

4. At least 50% of clients meet with 2 or more team members in a given quarter.
5. Full team meets at least weekly (expectation is 12 meetings per quarter).
6. Staff Meets as a Team. Each team member attends at least 80% of team meetings.
11. Each client’s clinical status is reviewed at least briefly at each meeting.
12. Team has developed a system for team communication, as needed, outside of team meetings.

Supervision

7. Team Leader provides clinical supervision to clinicians serving as the Primary Clinician and ORC at least bi-weekly for clinical supervision to review client progress, interventions attempted, and next steps.
8. Team Leader provides intensive, outcome-based supervision with respect to meeting clients’ goals for education and employment. Team leader conducts at least twice monthly SEES supervision during which each client on the team is reviewed with respect to education and employment outcomes to identify new strategies and ideas to help clients in their school and work lives.
9. Team leader provides at least bi-weekly supervision to the Peer Specialist to review engagement strategies for incoming clients and review of work with current clients.
10. Supervisees report that the TL meets with them on a regular basis to discuss client progress.

Caseload

26. Team’s caseload does not exceed a 12:1 ratio- based on the last day of any given quarter.
27. By the end of the past 6 months, team has at least 25 current clients.
28. Review the team’s census on site.

Enrollment/Discharge

Eligibility

13. Eligibility forms are completed and only clients meeting criteria are enrolled.
14. OnTrackNY records indicate that participants meet program’s eligibility criteria and there is evidence in the clients' records.
40. Eligibility evaluation includes: 1. Time course of symptoms, change in functioning and substance use; 2. Recent changes in behavior; 3. Risk assessment risk to self/others; 4. Mental status exam; 5. Psychiatric history; 6. Premorbid functioning; 7. Co-morbid medical illness; 8. Co-morbid substance use; 9. Family history
41. Assess client/family preferences and include incare plan needs related to: 1. Housing; 2. Employment; 3. Education; 4. Social support; 5. Finances; 6. Basic living skills; 7. Primary care access; 8. Social skills; 9. Family support; 10. Past trauma; 11. Legal
42. Patients, family and staff develop individualized treatment plan using evidence-supported treatments addressing client needs, goals and preferences (i.e. pharmacotherapy, psychotherapy, addictions, mood problems, suicide prevention, weight management).

Outreach

15. ORC visits each target hospital at least once each quarter, speaking with inpatient, outpatient, and ER clinical staff about OnTrackNY and leaving printed material.
16. In addition, each quarter the ORC will make outreach visits to other community settings, leaving printed material.
17. In the past 6 months, all settings noted in the Program Components form will receive some type of outreach (face to face, telephone, electronic).
18. ORC routinely builds and maintains relationships within referring community to establish referral network.
19. Community education about early episode psychosis routinely provided in referring community to key stakeholders.
31. Team can explain a concrete strategy to promote client engagement when clients miss appointments or show disinterest in services, which includes reaching out to people using various methods (e.g., phone, text, email, and home visits).

Referrals

20. For at least 80% of individuals admitted to the program, the time from eligibility determination to admission is < 1 week.
21. At least 65% of individuals went from screening to initial evaluation within 7 days.
22. At least 85% of individuals deemed eligible enter/enroll in the program.
23. Participants are screened by phone within 72 hours of contact for eligibility and scheduling of initial evaluation.
24. Participants are seen within one week of initial contact for initial eligibility evaluation.
25. If appropriate for the program, participants are scheduled for an intake evaluation with both PC and Prescriber within a week of eligibility determination.

Discharge

94. For at least 80% of clients who are discharged, that discharge occurs after team and client have worked together and established appropriate follow-up mental health services and community supports post discharge.
95. Interviews with Primary Clinicians, clients, and review of medical records indicate that PCs identify and provide linkages to community supports that clients and families may need for a successful transition.
96. Individual length of stay for enrolled clients will not exceed 36 months.
97. At least 80% percent of discharged clients attend their first appointment with a mental health or substance use treatment provider within 30 days of discharge.
98. At least 90% of discharged clients who were prescribed an antipsychotic medication at the time of discharge keep a follow up appointment with a psychiatrist or psychiatric nurse practitioner within 30 days of discharge.
99. Participants who are non-responsive to treatment or outreach are referred to appropriate treatment providers and appropriate follow up given for assurance of engagement
100. Interviews with Primary Clinicians, clients, and review of medical records indicate that teams are performing planned discharges and have a system for following-up to make sure clients are attending initial appointments with new providers.

Provision of Services

Services

29. At least 10% of clients are seen in the community by at least one Team member at least once per quarter (exclude services provided by the Supported Education and Employment Specialist).
30. Staff schedule shows the regular availability of office time outside of 9am to 5pm for the scheduling of routine appointments.

Crisis Services

32. Team provides 24/7 phone access to clients and families and team has a system in place in accordance with the host agency policy to manage crises, including access to medical back-up.
33. Team is involved in providing in-person crisis support or coordinating linkages to manage crises on a timely basis.

34. Team provides 24/7 phone access to clients and families and the policy is posted at the site in a location visible to clients/family members and distributed to each client.

35. Team has a system in place in accordance with the host agency policy to manage crises, including access to medical back-up.

36. Team is involved in providing in-person crisis support or coordinating linkages to manage crises on a timely basis.

Core Sessions

37. 70% of clients receive core sessions 1-5 within the first 6 months of working with the team.

38. Clinicians report receiving training on core care processes including recovery, person-centered care, shared-decision making, and cultural competency.

39. Clients report that the team is delivering person-centered care, using recovery principles, shared-decision making (e.g., watching the SDM video), and cultural competency.

Safety

45. The CSSR or equivalent tool is used with every client at admission and whenever concerns about possible suicide are raised.

46. For those who meet or exceed the specified threshold indicating a risk of suicide, a safety plan is developed the same day of the screening and is included in the chart.

47. Interviews with Primary Clinicians, clients, and review of medical records indicate safety plan intervention is being delivered.

48. Safety plan is available in the medical record for clients who endorse suicidal ideation plan or intent.

Family Involvement

76. For all clients, Team has conversations regarding their preferences for family involvement as part of the admission process.

77. For at least 50% of clients, at least one team member met with at least one member of the client’s family each quarter.

78. At least one family member group each month meets outside the hours of 9am-5pm M-F.

79. Interviews with Primary Clinicians, clients, and review of medical records indicate that Primary Clinicians offer meetings with client’s families and for those who agree, family meetings are happening depending on client and family preferences.

80. Primary Clinicians report that they are conducting at least one family session outside the hours of 9am-5pm M-F.

Substance

70. At least 90% of Admission and Follow-up forms indicate what, if any, substances were used during the quarter and whether this use was seen as problematic by the client and by the team.

71. Of clients whose substance use is seen as problematic by at least one member of the team (including the client), at least 50% of such clients are receiving treatment for substance use by meeting with at least one OnTrackNY clinician during the quarter.

72. There is evidence from interviews with Primary Clinicians that they use Motivational Interventions/Shared Decision Making/Harm Reduction strategies with clients who have substance use issues.

73. If substance use is a treatment goal, it is documented in the treatment plan and the medical record reflects that this is being worked on collaboratively with clients and the team.

Trauma

74. Interviews with Primary Clinicians, clients, and review of medical records indicate that routine assessments of PTSD are being performed with clients.

75. Interventions for trauma are delivered based on client preferences. Ask primary clinicians if they are familiar with the Brief PTSD intervention and whether they have used it with any clients. Ask clients if they were offered PTSD treatment and whether their preferences were considered.

Team Roles

Case Management

43. Interviews with Primary Clinicians, clients, and review of medical records indicate that Primary Clinicians routinely assess clients' and families' concrete needs.
44. Primary Clinicians provide case management services to help clients and families with concrete needs.

Psychoeducation

64. At least 75% of clients participate in at least five of the ten core sessions with the Primary Clinician.
65. Interviews with providers, clients, and medical records indicate that Primary Clinicians use psychoeducation routinely in care.

SEES

81. At least 90% of the SEES's time is devoted to assisting client in working on employment or education goals.
82. At least 50% of SEES' time is spent in community settings (outside the mental health center), devoted to engagement, employer and educational institution contacts, providing follow-along support, etc.
83. At least 50% of clients were competitively employed, in a competitive internship, or attended school as part of a degree-granting program at least 1 day per quarter.
84. On the last day of the quarter, at least 65% of enrolled clients were competitively employed, in a competitive internship, or attended school as part of a degree-granting program. For clients discharged during the quarter, consider their school/employment status on the day of discharge.
85. At least 90% of clients who have a goal of school or work indicated on their Follow-up form (or for newly admitted clients, on their Admission form), to have met with the SEES for help with school or employment.
87. Interviews with SEES and TL and medical records reflect that SEES spends most of their time helping clients find competitive jobs or returning to mainstream education as well as providing follow-along supports.
88. Medical records reflect work/school goals in the treatment plan and indicate whether clients are enrolled in school or have jobs.

Peer Specialist

89. For all clients, Team has conversations regarding their preferences for working with the Peer Specialist.
90. 50% of participants meet with the peer specialist at least once per quarter.
91. Interviews with Primary Clinicians, Peer Specialist, clients, and review of medical records indicate that clients and families are being offered meetings with the peer specialist.
92. Peer Specialist is engaged with team outreach activities and initial client engagement.
93. Peer Specialist works with clients using their recovery stories and provides support to clients around PC interventions.

CBT/MI

66. At least 30% of clients participate in at least one of the following skills building interventions with the Primary Clinician: coping skills, social skills, substance use treatment, behavioral activation.
67. At least one such group (family psychoeducation, substance use, social skills, coping skills, health & wellness) occurs at least monthly (to count as a group, family members of at least 2 clients must attend).
68. At least once per month, at least one such group occurs outside of normal business hours (outside of 9am-5pm, M-F).
69. Interviews with Primary Clinicians, clients, and medical records indicate that Primary Clinicians are using empirically-validated CBT-based interventions to match client problems based on client preferences.

Medical Services

Medications

49. On the last day of the reporting period, antipsychotic medication was prescribed for at least 60% of clients.
50. At least 75% of clients have had at least one trial of an antipsychotic medication prescribed for at least 4 continuous weeks within the recommended dosage range.

51. Psychiatrist or nurse practitioner records symptoms and side effects for each client prescribed psychotropic medication at least quarterly using standardized assessment scales in a manner that facilitates monitoring changes over time.
52. At least one client is on clozapine.
53. Evidence that antipsychotic medication was prescribed or discussed with clients.
54. Evidence in medical record that clients have had at least one trial of antipsychotic medication for at least 4 continuous weeks within the recommended dosage range.
55. Evidence that prescriber or nurse assess for side effects and standardized assessment scales can be found in the medical record.
56. Prescribers and clients report that client preferences are considered and SDM is used before medications are prescribed.

Metabolic

57. For at least 80% of clients prescribed an antipsychotic medication, weight is assessed at least quarterly. (Weight gain of over 1 BMI prompts consideration of a change (in medication, dosage, or behavioral intervention).
58. For at least 25% of clients prescribed an antipsychotic, assessment of fasting glucose/HbA1c and lipids is conducted at least quarterly.
63. Interviews with providers and medical records substantiate that team is performing weight assessments, requesting glucose and lipid levels, and working on wellness strategies with clients.

Nurse

59. At least 50% of clients meet individually (i.e., not as part of a group) with the nurse within 3 months of their admission date.
60. At least 80% meet individually with the nurse within 6 months of their admission date.
61. At least 45% of clients have completed a Core Session with the nurse about health and wellness services available via OnTrackNY within the first 6 months of treatment.
62. At least 35% of clients meet with the nurse at least once per quarter beyond the core session.

Appendix B

Participant Responses on WHO DAS Functioning Items

	Over the past 30 days, how much difficulty did you have…	**None**	**Mild**	**Moderate**	**Severe**	**Extreme / Cannot Do**
Cognition						
1	Concentrating on something for 10 minutes	39.3%	22.5%	24.7%	10.1%	3.4%
2	Analyzing and finding solutions to problems	21.4%	30.3%	30.3%	15.7%	2.3%
3	Remember to do important things	29.2%	23.6%	22.5%	19.1%	5.6%
4	Learning a new task, like how to get to a new place	38.2%	23.6%	22.5%	11.2%	4.5%
5	Generally understanding what people say	37.1%	27.0%	28.1%	5.6%	2.3%
6	Starting and maintaining a conversation	30.3%	23.6%	20.2%	14.6%	11.2%
Mobility						
7	Standing for long periods of time, such as 30 minutes	47.2%	22.5%	16.9%	10.1%	3.4%
8	Standing up from sitting down	55.1%	24.7%	12.4%	6.7%	1.1%
9	Moving around inside your home	56.2%	20.2%	13.5%	9.0%	1.1%
10	Getting out of your home	52.8%	25.8%	10.1%	10.1%	1.1%
11	Walking a long distance, such as a kilometer	58.4%	19.1%	12.4%	5.6%	4.5%
Self-Care						
12	Washing your whole body	64.0%	14.6%	13.5%	4.5%	3.4%
13	Getting dressed	70.8%	14.6%	9.0%	3.4%	2.3%
14	Eating	50.6%	14.6%	23.6%	6.7%	4.5%
15	Staying by yourself for a few days	51.7%	22.5%	9.0%	12.4%	4.5%
Relationships						
16	Dealing with people who you do not know	30.3%	30.3%	21.4%	14.6%	3.4%
17	Maintaining a friendship	39.3%	22.5%	18.0%	13.5%	6.7%
18	Getting along with people who are close to you	42.7%	24.7%	21.4%	6.7%	4.5%
19	Making new friends	38.2%	13.5%	19.1%	15.7%	13.5%
20	Sexual activities	66.3%	7.9%	7.9%	9.0%	9.0%
Life Activities and Household						
21	Taking care of your household responsibilities	42.7%	29.2%	13.5%	11.2%	3.4%
22	Doing most important household activities well	46.1%	27.0%	13.5%	9.0%	4.5%
23	Getting all of the household work done that you needed to	33.7%	30.3%	19.1%	7.9%	9.0%
24	Getting your household work done as quickly as needed	34.8%	25.8%	16.9%	16.9%	5.6%

	Over the past 30 days, how much difficulty did you have…	**None**	**Mild**	**Moderate**	**Severe**	**Extreme / Cannot Do**
Work or School						
25	Your day-to-day work or school	52.2%	23.2%	10.1%	8.7%	5.8%
26	Doing your most important work/school tasks well	43.3%	20.9%	20.9%	10.5%	4.5%
27	Getting all the work done that you needed to	48.5%	17.7%	19.1%	7.4%	7.4%
28	Getting your work done as quickly as needed	42.7%	20.6%	19.1%	11.8%	5.9%
Participation in Society						
29	How much of a problem did you have in joining in community activities (e.g., festivities, religious or other activities) in the same way as anyone else can	29.6%	22.7%	26.1%	9.1%	12.5%
30	How much of a problem did you have because of barriers or hindrances in the world around you?	25.0%	28.4%	23.9%	14.8%	7.8%
31	How much of a problem did you have living with dignity because of the attitudes and actions of others?	40.9%	21.6%	17.1%	15.9%	4.6%
32	How much time did you spend on your health condition, or its consequences?	28.4%	25.0%	30.7%	13.6%	2.3%
33	How much have you been emotionally affected by your health condition?	25.0%	17.1%	27.3%	23.9%	6.8%
34	How much has your health been a drain on the financial resources of you or your family?	34.1%	25.0%	21.6%	12.5%	6.8%
35	How much of a problem did your family have because of your health problems?	29.5%	25.0%	20.5%	19.3%	5.7%
36	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	34.1%	21.6%	18.2%	14.8%	11.4%