INFORMATION GUIDE

# Information Guide: Use of Performance Measures in Early Intervention Programs

Developed for SAMHSA by NRI and NASMHPD JBS Contract Reference: HHSS283201200002I/Task Order No. HHSS28342002T

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## Acknowledgements

This report would not have been possible without the knowledge and guidance shared by leaders at a handful of early intervention coordinated specialty care programs. Special thanks are extended to Lisa Dixon, M.D. and Susan Essock, Ph.D. (OnTrackNY); Tamara Sale, M.A. of the Early Assessment and Support Alliance (EASA); Tara Niendam, Ph.D. from the Sacramento Early Detection and Preventive Treatment Program (EDAPT); Jessica Pollard, Ph.D. of the Yale STEP program; Donald Addington, M.D. of the Calgary Early Psychosis Treatment Services (EPTS); Rachel Loewy, Ph.D., and Julia Godzikovskaya of the PREP and BEAM Programs; Vicki Montesano, Ph.D. and Christopher Buzzelli (Ohio Best Practices in Schizophrenia Treatment (BeST) Center's first episode psychosis (FIRST)) program; Ann Hackman, M.D., and Tiffany Spaulding, L.C.S.W. (Maryland RAISE Connection Program); and John Kane, M.D., and Patricia Marcy, R.N. (NAVIGATE).

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### Background and Introduction

In Fiscal Year 2014, the Consolidated Appropriations Act included a new requirement within the Mental Health Block Grant (MHBG), administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), that "States shall expend at least five percent of the amount each receives... to support evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders, regardless of the age of individuals at onset."<sup>1</sup> Congress specifically provided a five percent increase to the MHBG over prior-year levels to help states meet this



new requirement without losing funds for existing services. In December of 2015, when Congress enacted the Omnibus Appropriation for FY 2016 (Public Law 114-113), it included a 10% set-aside for first episode programming, again with new dollars added to facilitate compliance with the requirement. In addition to increasing the set-aside from 5% to 10%, there is also a slightly narrower focus beginning in FY 2016. Initially, the set-aside allowed for the support of evidence-based programming for a first episode of *any* serious mental illness or serious emotional disturbance, although the Congressional language did *highlight* psychosis and the coordinated specialty care model. In the Congressional committee report for the FY 2016 budget, however, language was included specifying that the funds must be used exclusively for first episode *psychosis*.

The additional funding is designed to bolster state programming to better identify and more adequately serve individuals experiencing their first episodes of serious mental illness (SMI), specifically psychosis. By identifying individuals experiencing their first episode earlier, and getting them engaged in assertive evidence-based services, these programs can help reduce the disability individuals may ultimately experience, and assist them in pursuing their life goals. In order to access behavioral health care in the public system, individuals are often required to meet criteria for serious and persistent mental illnesses, a threshold determined by each state. Individuals meeting these criteria generally already have significant, long-term disabilities when they begin receiving public mental health services. In fact, some states require that consumers meet duration and disability requirements to be eligible for services. While delivering services for persons with serious and disabling illnesses continues to be an important role for state behavioral health systems, the development of responsive programming for individuals experiencing their first episodes of such illnesses may eventually reduce the rates at which they become disabled, benefiting both the consumer, the community, and the treatment system.

<sup>&</sup>lt;sup>1</sup> DHHS. (2012). Department of Health and Human Services: fiscal year 2014 – Substance Abuse and Mental Health Services Administration. Department of Health and Human Services. <u>http://www.samhsa.gov/sites/de-fault/files/samhsa-fy2014-budget\_0.pdf</u>

The National Institute of Mental Health (NIMH) sponsored a set of studies, beginning in 2008, focusing on the early identification and provision of evidence-based treatments to persons who experience a first episode of psychosis (the Recovery After an Initial Schizophrenia Episode (RAISE) model). The NIMH RAISE Studies, as well as similar early intervention programs tested worldwide, consist of multiple evidence-based treatment components used in tandem as part of a coordinated specialty care (CSC) model, and have been shown to improve symptoms, reduce relapse, and prevent mental deterioration and disability. Common components of early intervention programs include practices such as assertive community treatment (ACT), psychotherapy, supported employment and education, family education and support, and medication management.

Using the MHBG set-aside funds, states are implementing a number of CSC program models and other services that utilize core principles and components of CSC. Under contract from SAMHSA, NASMHPD and NRI have been working with a Virtual Triage Team to guide the development of technical assistance products to serve as resources to help states make the best use of these important funds. One of the requests identified by the Virtual Triage Team was a report that summarizes the performance measures that current early intervention programs have found to be most useful in determining the effectiveness of their programs in mitigating the effects of serious mental illnesses.

The goals of this report are to provide a resource to help states and clinics identify the performance measures that are used and thought to be important by ongoing programs, as well as to help them identify performance measures to be considered when establishing an early intervention CSC program. To achieve these ends, a series of structured interviews with existing programs was conducted, and a structured research protocol was administered to capture their ratings of the usefulness and difficulty of collecting their performance measures. Based on the data from these interviews, this report provides an overview of performance measures used and why they may be important to states and clinics considering implementing an early intervention CSC program. This report also provides insight into the use of performance measures by nine first-episode CSC programs, specifically addressing the clinical and administrative utility, as well as the collection burden of each performance measure in use by the program. The following programs contributed significantly to the development of this report: OnTrackNY, Early



Assessment and Support Alliance (EASA), Early Diagnosis and Preventive Treatment (EDAPT)/SacEDAPT, FIRST Early Identification and Treatment of Psychosis Program, Yale Specialized Treatment Early in Psychosis (STEP), Calgary Early Psychosis Treatment Services, the Maryland RAISE Connection Program, NAVIGATE, as well as the Prevention and Recovery in Early Psychosis (PREP) and Bipolar Disorder Early Assessment and Management (BEAM) Programs.

### Methodology

Project staff worked with the program leaders from nine first-episode CSC programs (OnTrackNY, EASA, EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Yale STEP, Calgary EPTS, PREP/BEAM, Maryland RAISE Connection Program, and NAVIGATE) to better understand the utility and burden of each performance measure the program uses. Utility measures focused on how these measures are used to make administrative and clinical decisions. CSC programs were identified based on their participation in the Robert Wood Johnson Foundation/NIMH/SAMHSA September 2014 Prodromal and Early Psychosis Prevention Meeting, and through their subsequent contributions to the development of *An Inventory and Environmental Scan of Evidence-Based Practices for Treating Persons in Early Stages of Serious Mental Disorders.*<sup>2</sup> Project staff contacted each of the CSC programs to see if they would be willing to contribute to the development of this report. If so, the CSC program was asked to identify the contact person responsible for collecting and analyzing their performance measures to be interviewed for this report.

Program contacts were asked to complete a utility and burden assessment form that was tailored to each program based on a list of performance measures and/or instruments that they had reported in the environmental scan. Each measure or instrument was categorized into one of 10 domains (plus six sub-domains) that were identified as commonly employed in the environmental scan:



- · Identification, Intake, and Enrollment
- Program Involvement
- Improved Symptoms
- Functioning
  - Global Functioning
  - Employment
  - School Participation
  - Legal Involvement
  - Living Situation/Homelessness
  - Social Connectedness
- Suicidality
- Psychiatric Hospitalization
- Use of Emergency Rooms
- Substance Use
- Prescription Adherence and Side Effects
- Physical Health

<sup>&</sup>lt;sup>2</sup> NASMHPD, Inc., NRI, Inc. (2015). An Inventory and Environmental Scan of Evidence-Based Practices for Treating Persons in Early Stages of Serious Mental Disorders. SAMHSA. <u>http://media.wix.com/ugd/186708\_daa4f13b213b443db32b779216da156a.pdf</u>

The early intervention program contacts evaluated each of their performance measures or instrument's clinical utility, administrative utility, and collection burden on three separate five-point Likert scales (e.g., 1 = least useful, 5 = most useful: 1 = least burdensome, 5 = most burdensome). For the purposes of this report, clinical and administrative utility were defined as follows:

- Clinical utility specifically relates to information regarding the treatment and recovery plans for the consumer. How well does the measure/instrument help the consumer and treatment team adjust the treatment and recovery plans to better accommodate the changing clinical and social status of the consumer?
- Administrative utility relates to the administration of the treatment program. For instance, data on re-arrests or re-hospitalization can be useful for administrative utility when aggregated across the caseload. Process measures that evaluate the productivity of treatment and support staff are another example of an administratively useful data element.

An example of the utility/burden assessment completed by the program developers is included in Appendix A. Results from these utility/burden evaluation forms are summarized by domain. The utility/burden summary is included in the section *Evaluation of Performance Measures by Early Intervention CSC Programs.* 

Programs were given approximately two weeks to complete the utility and burden evaluations. Once the assessments were complete, project staff held follow-up interviews, lasting approximately 1.5 hours, with several of the contacts to better understand their responses to the structured questionnaire. Notes from each of these follow-up interviews are included in Appendix B. Table 1 indicates which programs completed which assessment:



#### Table 1: Status of Program Participation in Evaluations and Interviews

Program	Utility/Burden Evaluation	Telephone Interview
Calgary EPTS	Yes — Measure Specific	Yes
EASA	Yes — Measure Specific	Yes
EDAPT/SacEDAPT	Yes — Measure Specific	Yes
Maryland RAISE Connection Program	Yes — Measure Specific	No
NAVIGATE	Yes — Measure Specific	No
Ohio BeST Center's FEP (FIRST) program	Yes — Measure Specific	Yes
OnTrackNY	Yes — Instrument Specific	Yes
PREP/BEAM	Yes — Instrument Specific	Yes
Yale STEP	No	Yes

A brief review of the literature was conducted in August 2015 to enhance the understanding of performance measures in use by early intervention CSC programs. Sources were identified through internet and database searches. Keywords/phrases used in the searches include:

- What are performance measures?
- What are process measures?
- What are outcome measures?
- Performance measures psychosis
- Performance measures early intervention
- Performance measures to evaluate cost savings in clinical settings

CSC representatives who provided information about their program models were provided with a draft copy of the information presented and asked to review it for accuracy.



### Limitations

It is important to note that six of the programs contributing information for this report were initiated as research studies. As such, these programs were afforded additional funds, resources, time, and flexibility that may not be available to programs operated by the public mental health system, including providers funded with the MHBG Set Aside. Programs operating in the public system are likely limited by the type of tools they are able to administer, and outcomes they are able to collect (e.g., associated training costs and time to administer). For instance, the NAVIGATE program, which began as a research program, explicitly stated in response to our request

for information that the measures used by the program were exclusively collected for research purposes, and their corresponding utility and burden ratings are based upon the researchers' understanding of the scales, rather than the clinicians' experiences. Because of these limitations and excessive burden, the NAVIGATE program suggests that sites implementing their program collect "basic outcome data, such as days in school, days worked, hospitalization, Emergency Room visits, etc." with tools that require less intensive training and are easier to implement than measures used in their NIMH research study.

### List of Acronyms

ACT: Assertive Community Treatment ANSA: Adult Needs and Strengths Assessment BEAM: Bipolar Disorder Early Assessment and Management Program Calgary EPTS: Calgary Early Psychosis Treatment Services **CBT:** Cognitive Behavioral Therapy CGI: SCH: Clinical Global Impression Scale - Schizophrenia CRDPSSS: Clinician-Rated Dimensions of Psychosis Symptom Severity Scale CSC: Coordinated Specialty Care CSFRA: Client Symptom and Functioning Reassessment CSI: Colorado Symptom Index CSSRS: Columbia Suicide Severity Rating Scale EASA: Early Assessment and Support Alliance **EBP: Evidence-based Practice** EDAPT: Early Detection and Preventive Treatment EHR: Electronic Health Records ER: Emergency Room FEP: First Episode Psychosis GF-R: Global Functioning - Role GF-S: Global Functioning - Social **IRB: Institutional Review Board** MOTS: Measurement Online Tracking System MHBG: Community Mental Health Services Block Grant NASMHPD: National Association of State Mental Health Program Directors NIMH: National Institute of Mental Health NOMs: National Outcome Measures NRI: NASMHPD Research Institute PANSS: Positive and Negative Syndrome Scale PREP: Prevention and Recovery in Early Psychosis SacEDAPT: Sacramento Early Detection and Preventive Treatment SAMHSA: Substance Abuse and Mental Health Services Administration SED: Severe Emotional Disturbance SMI: Severe Mental Illness

# Use of Performance Measures to Evaluate Program Effectiveness

Early intervention programs rely on performance measures to document treatment effects for both consumers and the public mental health system. Performance measures consist of two types of metrics: outcome and process measures. Outcome measures are data indicators that are collected at baseline and at periodic intervals throughout treatment to objectively measure a consumer's status in specific areas (e.g., symptoms, hospitalization). Changes in these measures document an individual's progress in response to treatment (e.g., improvement in symptoms and functional status). Similar to outcome measures, process measures are used to objectively determine how well the early intervention program functions at administering services to consumers (e.g., program retention rates, aggregate decrease in duration of untreated psychosis, etc.), and how well the treatment team adheres to the CSC model with high fidelity. Process measures can also capture the type and volume of services delivered, encounters with the consumer and/or on his or her behalf with other agencies, etc. Performance measurement offers programs the following benefits<sup>3</sup>:

- Allows the clinic and the state to determine whether the program is successful at mitigating the illness and ultimately improving consumers' lives.
- Increases understanding of the processes of care; to confirm ideas, reveal unknown factors, and identify any issues with service delivery.
- Enables program leadership to present well-documented data to policy makers and potential funders to encourage continued or additional support for the program.
- · Highlights areas for improvement.
- · Reveals problems that bias, emotion, and longevity conceal.
- Identifies how well the clinical team works to achieve the goals established by the program.



It is especially important for early intervention CSC programs to monitor and evaluate performance measures from inception to ensure quality of service delivery. Applying performance measurement at program onset allows programs to establish goals, design services to meet these goals, and evaluate whether the services are successful at achieving the goals so it can make necessary adjustments to service delivery. It is also less burdensome to establish this framework at the beginning of a program, and make modifications to the framework later, rather than retrofitting a measurement system to an existing program and disrupting an established culture.

<sup>&</sup>lt;sup>3</sup> Oak Ridge Associated Universities. (2005). Benefits of performance measurement. <u>http://www.orau.gov/pbm/</u> documents/overview/benefits.html

# FACTORS TO CONSIDER WHEN SELECTING AND IMPLEMENTING PERFORMANCE MEASURES

When deciding which performance measures to collect, early intervention CSC programs should consider the following:<sup>4,5</sup>

- Purpose, or why the outcome is being measured
- · Patient-centeredness, or how well the measures reflect patient goals
- Effectiveness of treatment
- Efficiency and cost effectiveness of treatment
- Equity, or how effective treatment is across multiple demographics
- · Availability and accessibility of the data
- Method by which data are collected (e.g., paper forms with subsequent data entry, access to EHRs and medical records, etc.)
- Burden of data collection

In addition to the points mentioned above, it is also critical that persons administering the performance measurement tools, including clinicians when appropriate, be adequately trained to administer the protocols in a standardized manner. Inadequate training could result in unreliable data, and an inability to understand consumer outcomes. Early intervention programs should also establish clear and concise definitions for outcome



measures at the onset to avoid any ambiguity or confusion. For instance, the duration of untreated psychosis has the potential for many definitions. "Duration of untreated psychosis refers to the time elapsing between psychosis onset and treatment initiation."<sup>6</sup> Many agree on when the onset of psychosis occurs; however, there is much debate over the definition of "treatment initiation." Treatment initiation may refer to when a consumer receives their first dose of antipsychotic medication, or when they first enroll in a treatment program. Addressing definitional issues ensures data quality and usefulness for comparison across programs should the program elect to participate in a benchmarking collaborative with other first episode programs.

<sup>&</sup>lt;sup>4</sup> Lohr, K.N. (1988). Outcome measurement: concepts and questions. Inquiry. <u>http://www.ncbi.nlm.nih.gov/</u> pubmed/2966125

<sup>&</sup>lt;sup>5</sup> Velentgas, P., et al. (2013). Developing a protocol for observational comparative effectiveness research: a user's guide. Agency for Healthcare Research and Quality. <u>http://effectivehealthcare.ahrq.gov/index.cfm/</u> <u>search-for-guides-reviews-and-reports/?productid=1166&pageaction=displayproduct</u>

<sup>&</sup>lt;sup>6</sup> Polari, A., et al. (2011). Duration of untreated psychosis: a proposition regarding treatment definition. Early Intervention in Psychiatry. <u>http://www.ncbi.nlm.nih.gov/pubmed/22032548</u>



### **ESTABLISHING A DATA COLLECTION FRAMEWORK**

Early intervention programs should develop a data collection framework that reduces burden to clinicians and standardizes measurement by piggybacking wherever possible on data routinely collected for other purposes (e.g., claims data, electronic medical records). Administrators overseeing more than one program should create central data repositories to allow for comprehensive data analysis and the development of reports. The ability to extract data from statewide data system (e.g., Medicaid) facilitates the process of data collection and allows for a robust analysis of performance measures. The programs interviewed for this report use a variety of approaches to data collection and management, several of which are outlined in the bullets below.

- EASA maintains a central data collection system with a longitudinal database dating back to 2008 which is when the Oregon Health Authority began funding the program. Providers submit performance measure data to the data collection system once per quarter, or within one week of a client's referral, entry, or discharge (whichever is appropriate to ensure timely data submission). Providers report that this frequency is appropriate; any longer and they might be likely to forget details. In addition to the central database maintained by EASA, the State of Oregon also maintains a centralized data system, the Measurement Outcome Tracking System (MOTS) that collects a few of the same elements as EASA. EASA is currently negotiating with the state about how to access the MOTS data to reduce the data collection burden on providers.
- EDAPT/SacEDAPT does not currently maintain a central database that allows for comparisons across project sites; however, the program is working to develop an Access database to enable such comparisons. The program serves both publicly and privately-funded patients, which helps them reach a greater portion of the population; however, data are only collected on clients in the county system for performance measures, because private insurance will not allow clinicians to bill the full time to conduct the performance assessments, and only allow for reassessment once per year.
- The BeST Center maintains a central database that collects outcome information from provider sites. In addition, the BeST Center collects and maintains data from participating sites by exchanging two standardized files: a master spreadsheet that monitors participation in each program, and service utilization data that tracks frequency and duration of services in anonymized form. Providers submit data monthly. Personnel from the BeST Center provide technical assistance to provider sites on how to manipulate data to facilitate visual comprehension, including the development of pivot tables and graphs in Excel, to submit to the program.

- Each OnTrackNY site uses the same approach to submit data to a centralized database. Currently, the majority of forms used by the program are scannable, with data sent to the Performance Measurement and Evaluation (PME) unit at the New York State Office of Mental Health; however, PME is in the process of implementing a secure web-based data-entry portal through which each team will enter the data currently being collected on the scannable forms. PME stores the data confidentially and provides customized reports to the OnTrackNY training team, which can then review data with individual teams. This process allows assessment of overall team performance and comparison across teams. Data are collected both on individual clients and quarterly on overall team functioning (e.g., staffing, hours of operation, off-hour coverage).
- STEP maintains a clinical database that is updated weekly in rounds for vocational status, symptom remission, and participation in interventions. A separate research database collects baseline, six month, and 12 month patient evaluations of extensive measures. STEP is developing a "clinical dashboard" that will allow clinicians to update key data points (e.g., PANSS score, vocational status, weight) as part of documentation of clinical visits and to facilitate ease of assessing clinic performance on benchmarks.



### Uses for Performance Measurement Data

#### BENCHMARKING

The set-aside funds, coupled with the promising findings from the NIMH RAISE (Recovery After an Initial Schizophrenia Episode) study, have triggered the rapid development of many early intervention CSC programs across the United States. The development of many programs simultaneously may provide a unique opportunity for the development of a standard set of performance measures to be used for national benchmarking.

Early intervention CSC programs can establish either informal or formal benchmarking collaboratives. Informal collaboratives consist of a group of organizations that "agree to certain principles and practices, such as metrics included, operational definitions, data-sharing methods, frequency of sharing [data], vehicles for communication (e.g., in person, conference calls, emails), and the use of technology."<sup>7</sup> Formal benchmarking processes take the components of informal benchmarking and better organize them around data submission protocols, and report generation procedures that "are confidential, automated, and conducted under controlled, rigorous standards to help ensure uniformity and accuracy."<sup>8</sup> Sample sizes tend to be larger in formal benchmarking networks, allowing for "more reliable and valid comparisons," with "deliverables [that] are highly beneficial, both quantitatively and qualitatively," whereas results from informal benchmarking networks tend to be qualitative (rather than quantitative) by nature.<sup>9</sup>

Benchmarking enables programs to rapidly identify weaknesses, make program improvements, and document best practices in early intervention programs. Without benchmarks, early intervention CSC programs may have little idea of how well they are doing when compared to other similar programs. Benchmarking also allows programs and researchers to document population health improvement and cost savings for funding sources on regional, statewide, and national levels.



 <sup>&</sup>lt;sup>7</sup> Lefkovitz, P. (2013). Benchmarking in behavioral health: Giving meaning to measurement, bringing data to life." Netsmart. <u>http://www.ntst.com/demos\_white-papers\_seminars/white\_papers\_live/WP\_Benchmarking\_2-13.pdf</u>
 <sup>8</sup> Id
 <sup>9</sup> Id

### **INVESTIGATING COST SAVINGS**

Early intervention programs have shown early promise at mitigating the impact of severe mental illnesses. In 2014, state behavioral health authorities expended \$40 billion to provide state mental health services. This figure does not take into account the amount other state agencies (such as Medicaid and Corrections) spend on providing services to persons with mental illness, or the financial impact to the overall economy through lost wages while people are unable to work or whose productivity is significantly compromised. State mental health systems exist in an increasingly competitive environment for funding; therefore, it is critical that early intervention programs be able to estimate cost savings and cost effectiveness to policy makers and other funders to sustain current funding levels and encourage new funding. Several of the first episode programs interviewed for this report attempted basic cost analyses as detailed below.

- A recent study in Oregon demonstrated a 33% decrease in cost and service utilization at Coordinated Care Organizations for individuals enrolled in early psychosis programs. EASA, implemented statewide in Oregon, plans to follow-up on these findings to investigate additional cost savings through decreased hospital admissions and ER use. EASA has attempted to use program data to interpret reduced hospitalization costs, but has faced challenges with data quality.
- Calgary's EPTS program also attempted to estimate cost savings by demonstrating a reduction in the two-year relapse rate from 60 percent to 30 percent. Although a protocol was developed for a randomized controlled cost-effectiveness study, it was not funded for completion.
- Ohio BeST reviewed service utilization data for clients who had been enrolled in their first episode psychosis (FIRST) program for 12 months. Because only 24 clients had been enrolled for 12 full months, the sample was too small for accurate statistical analysis. However, the BeST Center was able to determine that the cost to enroll a client in the FIRST program was approximately \$790 per month primarily using Ohio Medicaid mental health outpatient service rates. These estimates reflect average service use per member, per month for FIRST. The BeST Center found that all clients tend to use case management services heavily after they first enroll in the program. However, case management usage tends to taper off, to approximately 30 minutes per month after a client has been enrolled in the program for a year. This information is especially important for agencies that are planning new early intervention programs. Because the costs for individuals are likely to decrease after clients have been enrolled for a year, capacity gains may be easier to maintain.

• An article published in January 2016 in Schizophrenia Bulletin, "Cost Effectiveness of Comprehensive, Integrated Care for First Episode Psychosis in the NIMH RAISE Early Treatment Program," details the results of a cost effectiveness study conducted by a team of researchers led by John Kane, M.D., and Robert Rosenheck, M.D. Over the course two years, researchers evaluated the outcomes of 406 individuals at 34 clinics across the U.S. who received either the NAVIGATE early treatment model (223) or traditional care (181). The study found that although the NAVIGATE program cost 27 percent more than traditional care, outcomes for participants in the NAVIGATE program improved their quality of life by 13 percent over those receiving usual care. When monetizing the benefits of treatment using a standard cost-benefit analysis approach, the researchers found that the additional costs associated with coordinated specialty care models were outweighed by the benefits in improved quality of life. Additionally, one of the primary expenses of the NAVIGATE program, the cost of patented antipsychotic medications, is likely to decrease as generic versions of these medications become available.<sup>10</sup>



An example of how historical data can be analyzed to determine cost savings was recently published in the Journal of Mental Health Policy Economics. The study investigated "whether the introduction of an early intervention service in psychosis resulted in any change to the number and duration of admissions in people with first episode psychosis." The researchers evaluated two cohorts of individuals that presented with first-episode psychosis during two different periods. The first cohort,

presenting from 1995 to 1998, received treatment as usual. The second cohort, presenting between 2008 and 2011 received services from an early intervention CSC program. Data from the second cohort who received the early intervention services revealed significant reductions in the duration of untreated psychosis, and the average cost of admission declined from \$15,821 to \$9,398.<sup>11</sup>

<sup>&</sup>lt;sup>10</sup> Rosenheck, R., et al. (2016). "Cost Effectiveness of Comprehensive, Integrated Care for First Episode Psychosis in the NIMH RAISE Early Treatment Program." Schizophrenia Bulletin. 31 Jan 2016. <u>http://schizophreniabulletin.oxfordjournals.org/content/early/2016/01/19/schbul.sbv224.abstract</u>

<sup>&</sup>lt;sup>11</sup> Behan, C., et al. (2015). Estimating the cost and effect of early intervention on inpatient admission in first episode psychosis. Journal of Mental Health Policy Economics. <u>http://www.ncbi.nlm.nih.gov/pubmed/26231001</u>

## Evaluation of Performance Measures by Early Intervention CSC Programs

Eight of the nine early intervention CSC programs that provided information for this report completed the structured questionnaire to evaluate the utility and burden of performance measures and/or the tools used to collect performance measures (EASA, NAVIGATE, Maryland RAISE Connection Program, Calgary EPTS, EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) Program, OnTrackNY, and PREP/BEAM). Of these, six completed the evaluations based on individual questions contained within evaluation tools (e.g., "number of hours worked," "highest level of education completed," etc.), while two programs evaluated the utility and burden of the overall instruments used for data collection (e.g., the SCID, SIPS, etc.). Summaries of the utility and burden assessments for the individual questions (separated by domains), as well as the utility and burden of the tools used to collect the measures are included in this section.

# EVALUATION OF THE UTILITY AND BURDEN OF PERFORMANCE MEASURES AND DOMAINS

Developers were asked to evaluate the clinical and administrative utility, as well as the collection burden, of measures based on domains of performance measurement, including:

- · Identification, Intake, and Enrollment
- Program Involvement
- Improved Symptoms
- Functioning
  - Global Functioning
  - Employment
  - School Participation
  - Legal Involvement
  - Living Situation/Homelessness
  - Social Connectedness
- Suicidality
- Psychiatric Hospitalization
- Use of Emergency Rooms
- Substance Use
- Prescription Adherence and Side Effects
- · Physical Health



All domains received moderate to high clinical utility scores. On average, the highest clinical utility ratings were applied to measures in the Living Situation (average clinical utility of 4.92) and School Participation (4.66) sub-domains, and Suicidality (4.65). Measures in the Global Functioning sub-domain received the lowest clinical utility scores (3.27). The Living Situation and Suicidality domains also had the lowest average data collection burden, each with an average collection burden score of 1.23. Measures in the Identification, Intake and Enrollment; and the Global Functioning and Employment sub-domains of Functioning had the highest data collection burden (2.91, 2.86, and 2.82, respectively). Figure 1 shows the average clinical utility ratings for each of the domains, along with their corresponding collection burden ratings. For comparison purposes, the Functioning sub-domains are evaluated individually, as well as part of an overall functioning domain.

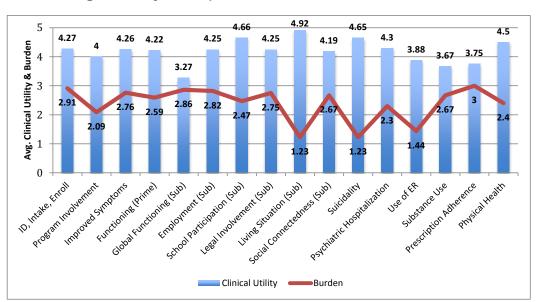
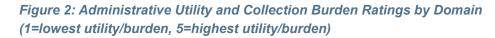


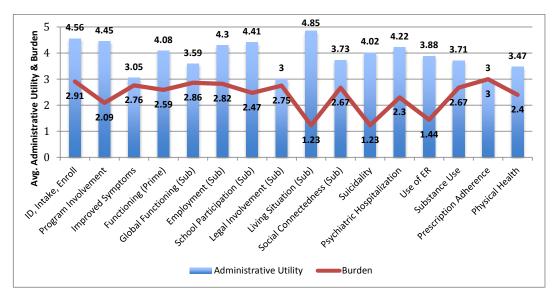
Figure 1: Clinical Utility and Collection Burden Ratings by Domain (1=lowest utility/ burden, 5=highest utility/burden)

Similarly, all domains were evaluated as having moderate or high administrative utility. The domains and sub-domains with the highest administrative utility are Living Situation (average administrative utility of 4.85) and Identification, Intake, and Enrollment (4.56). While nearly all domains were evaluated as having high administrative utility (scored greater than or equal to 4), three domains received moderate administrative utility evaluations: Improved Symptoms (3.08), Legal Involvement (3.00), and Prescription Adherence (3.00). Figure 2 on the following page shows the average administrative utility for each of the domains along with their corresponding collection burden scores.









In addition to providing quantitative ratings of performance measures, program developers were asked during the follow-up interviews which specific questions they would most recommend to states implementing a new early intervention program. Their recommendations are as follows (*note: due to restricted availability, follow-up interviews were not held with the Maryland RAISE Connection Program or NAVIGATE*):

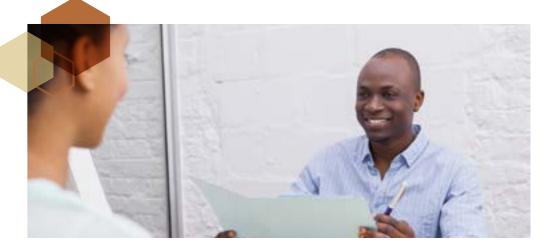




Table 2: Performance Measures Recommended by Early Intervention Programs

Domain	Measure	Comments	Recommended By
Identification, Intake and Enrollment	Incidence Rate for Population in Service Area Referral Source Who is Referred Who is Screened Out Time to Referral Duration of Untreated Psychosis	Incidence rate is important to ensure program reaches appropriate population. Referral information is extremely helpful to determine accuracy and impact of community education activities.	EASA Calgary EPTS OnTrackNY BeST Center STEP
Program Involvement	Family Involvement Service Use	Evaluating service use may enable accurate cost analysis.	EASA PREP/BEAM OnTrackNY BeST Center STEP
Functioning	All Global Functioning All Employment All School Participation Social Connectedness: Quality of Life Relationships with Family and Friends	All measures in the Global Functioning, Employment, and School Participation sub-domains are useful; especially those related to goals. These measures in the Employment and School Participation sub-domains in particular draw attention to policy makers.	EASA PREP/BEAM BeST Center OnTrackNY STEP
Psychiatric Hospitalization	Length of Stay Commitment Status Readmission		EASA OnTrackNY STEP
Emergency Room Use	All		OnTrackNY BeST Center
Physical Health	Insurance Status Metabolic indicators, including BMI	Has been extremely helpful in program sustainability discussions.	EASA OnTrackNY BeST Center STEP
Substance Use	All		OnTrackNY BeST Center STEP
Prescription Adherence and Side Effects	Medication Compliance Side Effects		BeST Center OnTrackNY STEP

Based on the utility and burden evaluations, as well as through information gleaned from the follow-up interviews, measures that indicate how well a consumer is functioning in the community are among the most important. This includes measures in the employment, school participation, and social connectedness domains. Other domains of importance are the identification, intake, and enrollment process; program involvement; psychiatric hospitalization; physical health; and prescription adherence and medication side effects. Within these domains, utility of measures varied.

The following series of tables presents a color-coded summary of the utility and burden ratings. To assist in interpretation of the table, each utility and burden score is color coded with green being the least burdensome and/or most useful, yellow intermediate, and red indicating the greatest collection burden and the lowest utility. Items that are displayed as green across the three dimensions are the most desirable while those with three red ratings have the greatest burden and lowest utility.

# Table 3: Domains and Measures with the Highest Rated Utility(1=lowest utility/burden, 5=highest utility/burden)

Measure	Clinical Utility	Administrative Utility	Collection Burden
Domain: Identification, Intake and Enrollment			
Population-based admission rate	5	5	3
Proportion of referrals to program that were first admitted to inpatient services	5	5	2
Median duration of untreated psychosis	5	5	3
Did the staff meet with the client in the community or client's preferred setting as part of the screening/ engagement process?	5	5	3
Were any client natural supports (family or friends) involved in the screening?	5	5	3
Does the client have natural supports (family or friends) who are willing to participate?	5	5	3
Does the client want natural supports (family or friends) participate in the treatment?	5	5	3
Domain: Program Involvement			
Proportion declining follow-up at one year/two years/three years.	5	5	2
Was the client discharged or transferred out of the program? If yes, why, and did they have a transition plan?	4	5	2
Which treatments has the client participated in during the past month?	4	4.5	2
LEGEND			
Least burdensome and/or most useful		Greatest burden least useful	and/or
Intermediate burden and/or usefulness		N/A	



		Tabl	e 3 continue
Measure	Clinical Utility	Administrative Utility	Collection Burden
Which treatments have family members/support persons participated in in support of the client during the last month?	4	4.5	2
Since your last assessment, which staff members have you or your family received support from? Where did this support occur?	4	4.5	2
Was the client discharged or transferred out of the program? If yes, why, and did they have a transition plan?	4	5	2
Functioning Sub-Domain: Employment			
Employment status	5	5	5
Hours worked per week	5	5	3
How long have you held this job?	5	5	3
Source of income	5	5	3
Status of benefits	5	5	3
Functioning Sub-Domain: School Participation			
If not working, volunteering, or in school, what are your current goals (for a job or school)?	5	5	3
What type of school do you attend?	5	5	2.5
How are your grades? Are you failing any classes?	5	5	3
Functioning Sub-Domain Social Connectedness			
Status of relationships with family and friends	5	5	3
What are your goals for your social life?	5	5	3
Psychiatric Hospitalization			
Hospitalization (type, including crisis stabilization, private psychiatric inpatient unit at hospital, state psychiatric inpatient unit, ER visit, etc.)?	5	4.33	3
Percentage of patients who have at least one admission to a hospital inpatient psychiatric unit by one year/two years/three years from admission to program	5	5	2
Physical Health			
Weight (percent with BMI <25 at one/two/three years)	5	3	2
Does client have primary care physician?	4.7	4.3	2.3
Insurance status	4.7	3.3	2.7
LEGEND			
Least burdensome and/or most useful		Greatest burden least useful	and/or
Intermediate burden and/or usefulness		N/A	

Table 3 continued

Measure	Clinical Utility	Administrative Utility	Collection Burden	
Prescription Adherence and Side Effects				
Assessment of Tardive Dyskinesia	5	3	3	
Maintenance dose medication within dosing guidelines	5	3	N/A	
Medication compliance	5	5	3	
Suicidality				
If you have thought about killing yourself in the past week, do you have a plan? If yes, what specifically are you thinking of doing?	5	5	1	
If you have tried to kill yourself, did you want to die?	5	5	1	
If you have tried to kill yourself, did you start psychiatric treatment within the month after you tried to kill yourself?	5	5	1	
Have family members talked about killing themselves? If yes, who and relationship?	5	5	1	
Has anyone in your family tried to kill him/herself? If yes, who and relationship/	5	5	1	
Do you know anybody who has tried to kill him/herself? If yes, who and relationship?	5	5	1	
Do you know anybody who has killed him/herself? If yes, who and relationship?	5	5	1	
LEGEND				
Least burdensome and/or most useful Greatest burden least useful				
Intermediate burden and/or usefulness		N/A		

Table 3 continued

### **EVALUATION OF PERFORMANCE MEASURES BY DOMAIN**

Detailed information about the questions or data elements used in each of these domains is included in the subsections below. In this section, the source for obtaining the information is listed in the second column. Often these sources refer to specific instruments that are used by each of the programs. Please reference the table of acronyms to identify the multi-component instruments that are referenced. The overall average clinical, administrative utility and burden scores are summarized before each section. When appropriate, contextual information from follow-up interviews or from comments received on the utility/burden evaluations is included in the final column (comments) in each matrix.

### DOMAIN: IDENTIFICATION, INTAKE AND ENROLLMENT

Measures in the Identification, Intake and Enrollment domain allow early intervention programs to determine how effective their efforts are at reaching and engaging potential consumers in treatment. These measures provide information about how successful the program's community outreach and education efforts are at ensuring appropriate referrals are made to the program, where contacts are made (in clinical setting or in the community), potential of family involvement in treatment, admission decisions, and the amount of time it takes between referral and enrollment.

Measures in this domain were evaluated as having high clinical and administrative utility (scored from 1 = low utility, to 5 = high utility), with a low to moderate collection burden (scored from 1 = low burden, to 5 = high burden):

- Average Clinical Utility: 4.27
- Average Administrative Utility: 4.56
- Average Collection Burden: 2.91

Table 4 lists each of the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that only three early intervention programs (EASA, Ohio BeST Center's FEP (FIRST) Program, and Calgary EPTS) provided quantitative evaluations of the utility and burden of specific measures in this domain.

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Domain: Identification	Domain: Identification, Intake and Enrollment							
Time from referral to first appointment	Admin. Records BeST Center Master Spreadsheet*	4.5	5	1	BeST Center Master Spreadsheet*			
Population-based admission rate	Admin. Records	5	5	3	The biggest challenge is identifying the population. This is easy for counties if they represent catchment areas.			
LEGEND								
Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A								
Intermedia	ate purden and/or	usetuine	SS	N/A				

# Table 4: Utility and Burden Evaluation of the Identification, Intake and Enrollment Domain

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Proportion of referrals to program first admitted to inpatient services	Admin. Records	5	5	2	This needs to be identified as an admission for psychosis. The burden is variable depending on the local system.		
Median duration of untreated psychosis	Admin. Records SIPS	5	5	3	Challenge with definition of treatment onset		
Contacts made through community outreach (educational programs, media campaigns, mailing list sign ups)	EASA Education and Outreach Form BeST Center Outreach Protocol	4	5	3			
Did the staff meet with the client in the community or client's preferred setting as part of the screening/ engagement process?	EASA Intake Form	5	5	3	The community could be the client's preferred setting		
Were any client natural supports (family or friends) involved in the screening?	EASA Intake Form	5	5	3			
Does the client have natural supports (family or friends) who are willing to participate?	EASA Intake Form	5	5	3			
Does the client want natural supports (family or friends) to participate in the treatment?	EASA Intake Form	5	5	3			
LEGEND							
Least bure	Least burdensome and/or most useful Greatest burden and/or least useful						
	ate burden and/oi	r usefulne	ss	N/A			

Table 4 continued

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
How was the client/ family referred?	EASA Referral and Decision Form BeST Center Master Spreadsheet*	4	4	3	Information about everyone referred and disposition. *The BeST Center monitors this information in the master spreadsheet; utility/burden evaluation for this measure is unavailable.	
Is this the referent's first referral to EASA?	EASA Referral and Decision Form	4	4	3		
Referral Decision	EASA Referral and Decision Form BeST Center Master Spreadsheet*	4	4	3	*The BeST Center monitors this information in the master spreadsheet; utility/burden evaluation for this measure is unavailable.	
Primary and Secondary Diagnosis	BeST Practices Outcome Review Form	5	5	3		
LEGEND						
Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A						

#### Table 4 continued

### DOMAIN: PROGRAM INVOLVEMENT

Measures in the Program Involvement domain allow early intervention programs to track how engaged the consumer, their families, and social supports are in the treatment plan. Items in this domain provide information about which services the consumer participated in, whether they switched from one counselor to another, how much the consumer's family participated in treatment, and whether the client was discharged from the program or left against medical advice.

Measures in this domain were evaluated as having moderate-to-high clinical and administrative utility, with a low collection burden:

- Average Clinical Utility: 4.00
- Average Administrative Utility: 4.45
- Average Collection Burden: 2.09

Table 5 lists each of the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that three early intervention programs (EASA, Calgary EPTS, and EDAPT/SacEDAPT) provided quantitative evaluations of the utility and burden of the questions in this domain.



#### Table 5: Utility and Burden Evaluation of the Program Involvement Domain

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Domain: Program Invo	olvement					
Which treatments has the client participated in during the past month?	CSFRA Utilization Data* Activity log*	4	4.5	2	*The BeST Center & STEP monitors this information; utility/ burden evaluation for this measure is unavailable.	
Family participation in screening and willingness to be involved.	CSFRA, EASA Intake Form	3.5	3.8	2		
Which treatments have family members/ support persons participated in in support of the client during the last month?	CSFRA	4	4.5	2		
Since your last assessment, which staff members have you or your family received support from? Where did this support occur?	CSFRA	4	4.5	2		
Proportion declining follow-up at one year/ two years/three years.	Admin. Records	5	5	2	This is a routine part of admission and discharge information if counted simply as admission and discharge for reasons other than moving away.	
LEGEND						
Least burdensome and/or most useful Greatest burden and/or						
Intermedia	ite burden and/or	usefulne	SS	N/A	useful	

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Did the client experience a change in primary counselor in the last three months/ this quarter?	EASA Outcome Review Form	3	5	1				
What type of services did the treatment team provide?	EASA Outcome Review Form Utilization Data*	3	3	4	Accuracy is an issue with this measure, making it more difficult to interpret. There are too many categories of service types, and it does not address frequency. Use of administrative records may improve the value of the measure; however, the records do not get at all of the possible subcategories *The BeST Center monitors this information; utility/ burden evaluation for this measure is unavailable.			
Was the client discharged, transferred out of the program? If yes, why, and did they have a transition plan?	EASA Outcome Review Form BeST Center Master Spreadsheet*	4	5	2	Definitions have been an issue (i.e., what constitutes treatment completion, and at what point can someone be discharged because they are "not appropriate" for the program). *The BeST Center monitors this information in the master spreadsheet; utility/burden evaluatio for this measure is unavailable.			
Least burc	Least burdensome and/or most useful Greatest burden and/or least useful							

					Table 5 continued		
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Do you have family members/support persons participating in your care at the program? If no, can we do anything to help you develop your support network?	CSFRA	4	4.5	2			
LEGEND	LEGEND						
Least burdensome and/or most useful Greatest burden and/or least useful							
	te burden and/or	usefulne	SS	N/A			

### DOMAIN: IMPROVED SYMPTOMS

Symptom measures enable early intervention programs to assess how well the treatments work to mitigate symptoms of severe mental illnesses, including the frequency and severity of symptoms; and the presence of positive, negative, depressive, and cognitive symptoms.

Measures in this domain were evaluated as having high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 4.26
- Average Administrative Utility: 3.05
- Average Collection Burden: 2.76

Table 6 lists each of the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Four early intervention programs (Maryland's RAISE Connection Program, NAVIGATE, Ohio BeST Center's FEP (FIRST) program and EDAPT/SacEDAPT) provided quantitative evaluations of the utility and burden of the measures in this domain.





Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Domain: Improved Symptoms						
Severity of Illness: Positive Symptoms	CGI-SCH, and CSFRA	5	5	2		
Severity of Illness: Negative Symptoms	CGI-SCH, and CSFRA	5	5	2		
Severity of Illness: Depressive Symptoms	CGI-SCH, and CSFRA	5	5	2		
Severity of Illness: Cognitive Symptoms	CGI-SCH, and CSFRA	5	5	2		
Severity of Illness: Overall Severity	CGI-SCH, and CSFRA	5	5	2		
Degree of Change: Positive Symptoms	CGI-SCH, and CSFRA	5	5	2		
Degree of Change: Negative Symptoms	CGI-SCH, and CSFRA	5	5	5		
Degree of Change: Depressive Symptoms	CGI-SCH, and CSFRA	5	5	5		
Degree of Change: Cognitive Symptoms	CGI-SCH, and CSFRA	5	5	5		
Degree of Change: Overall Severity	CGI-SCH, and CSFRA	5	5	5		
Presence of Hallucinations	CRDPSSS	5	5	3		
Presence of Delusions	CRDPSSS	5	5	3		
Presence of Disorganized Speech	CRDPSSS	5	5	3		
Presence of Abnormal Psychomotor Behavior	CRDPSSS	5	5	3		
Presence of Negative Symptoms (restricted emotional expressions or avolition)	CRDPSSS	5	5	3		
Presence of Impaired Cognition	CRDPSSS	5	5	3		
Presence of Depression	CRDPSSS	5	5	3		
Presence of Mania	CRDPSSS	5	5	3		
LEGEND						
Least burg	lensome and/or r	most useful		Greatest I least usef	burden and/or ful	
Intermedia	ate burden and/or	usefulness		N/A		

Table 6: Utility and Burden Evaluation of the Measures in the Improved

Symptoms Domain

Information Guide: Use of Performance Measures in Early Intervention Programs

Table 6 continued						
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Suspiciousness: Presence of in the last seven days	4-Item Positive Rating Scale	5	4	1	This tool, and the measures contained within, is very clinically useful to track the client's symptoms and duration. This information is collected every three months, which allows the team to identify if specific features of schizophrenia have improved. This also helps administratively to track the effectiveness of interventions.	
Unusual Thought Content: Presence of in the last seven days	4-Item Positive Rating Scale	5	4	1	See above	
Hallucinations: Presence of in the last seven days	4-Item Positive Rating Scale	5	4	1	See above	
Conceptual Disorganization: Presence of in the last seven days	4-Item Positive Rating Scale	5	4	1	See above	
Prolonged time to respond (alogia)	Brief Negative Symptoms Assessment Scale	5	4	1		
Emotion: unchanging facial expression, blank expressionless face (flat effect)	Brief Negative Symptoms Assessment Scale	5	4	1		
Reduced social drive (asociality)	Brief Negative Symptoms Assessment Scale	5	4	1		
LEGEND						
Least burc	lensome and/or r	nost useful		Greatest l least usef	burden and/or ful	
Intermedia	ite burden and/or	usefulness		N/A		

### Table 6 continued

					Table 6 continue	
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Grooming and hygiene (amotivation)	Brief Negative Symptoms Assessment Scale	5	4	1		
Presence of delusions	PANSS	4	2	3		
Presence of conceptual disorganization	PANSS	4	2	3		
Presence of excitement	PANSS	4	2	3		
Presence of grandiosity	PANSS	4	2	3		
Presence of suspiciousness/ persecution	PANSS	4	2	3		
Presence of hostility	PANSS	4	2	3		
Presence of blunted affect	PANSS	4	2	3		
Presence of emotional withdrawal	PANSS	4	2	3		
Presence of poor rapport	PANSS	4	2	3		
Presence of passive/ apathetic social withdrawal	PANSS	4	2	3		
Presence of difficulty in abstract thinking	PANSS	4	2	3		
Lack of spontaneity and flow of conversation	PANSS	4	2	3		
Presence of stereotyped thinking	PANSS	4	2	3		
Presence of somatic concern	PANSS	4	2	3		
Presence of anxiety	PANSS	4	2	3		
Presence of guilt feelings	PANSS	4	2	3		
Presence of tension	PANSS	4	2	3		
Mannerisms and posturing	PANSS	4	2	3		
Presence of depression	PANSS	4	2	3		
Motor retardation	PANSS	4	2	3		
LEGEND						
Least burd	lensome and/or r	nost useful		Greatest l least usef	burden and/or ful	
Intermedia	ite burden and/or	usefulness		N/A		

Table 6 continued

Table 6 continued						
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Uncooperativeness	PANSS	4	2	3		
Unusual thought content	PANSS	4	2	3		
Disorientation	PANSS	4	2	3		
Poor attention	PANSS	4	2	3		
Lack of judgment and insight	PANSS	4	2	3		
Disturbance of volition	PANSS	4	2	3		
Poor impulse control	PANSS	4	2	3		
Preoccupation	PANSS	4	2	3		
Active social avoidance	PANSS	4	2	3		
Depression: How would you describe your mood over the last two weeks? Do you keep reasonably cheerful or have you been depressed or low-spirited lately? In the last two weeks, how often have you (own words) every day? All day?	Calgary Depression Scale	3	2	3		
Hopelessness: How do you see the future for yourself? Can you see any future, or has life seemed quite hopeless? Have you given up or does there still seem some reason for trying?	Calgary Depression Scale	3	2	3		
Self Deprecation: What is your opinion of yourself compared to other people? Do you feel better, not as good, or about the same as others? Do you feel inferior or even worthless?	Calgary Depression Scale	3	2	3		
LEGEND						
Least burdensome and/or most useful Greatest burden and/or						
Intermedia	ite burden and/or	usefulnese		least usef N/A	ūl	

Table 6 continue						
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
Guilty Ideas of Reference: Do you have the feeling that you are being blamed for something or even wrongly accused? What about?	Calgary Depression Scale	3	2	3		
Pathological Guilt: Do you tend to blame yourself for little things you may have done in the past? Do you think that you deserve to be so concerned about this?	Calgary Depression Scale	3	2	3		
Morning Depression: When you have felt depressed over the last two weeks, have you noticed the depression being worse at any particular time of day?	Calgary Depression Scale	3	2	3		
Early Wakening: Do you wake earlier in the morning that is normal for you? How many times a week does this happen?	Calgary Depression Scale	3	2	3		
Observed Depression: Based on interviewer's observations during the entire interview. The question, "Do you feel like crying?" used at appropriate points in the interview may elicit information useful to this observation.	Calgary Depression Scale	3	2	3		
Considering your total clinical experience with people with schizophrenia, how mentally ill is the patient at this time?	Clinician- Version Clinical Global Impressions: Severity Scale	3	2	1		
LEGEND						
Least burd	ensome and/or r	nost useful		Greatest l least usef	burden and/or ul	
Intermedia	te burden and/or	usefulness		N/A		

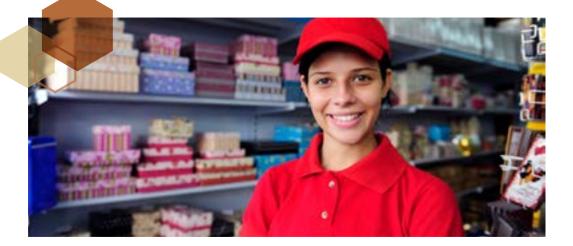
### **DOMAIN: FUNCTIONING**

The functioning domain includes 120 measures across six sub-domains that reflect how well an individual receiving treatment is able to be successful in the community. These sub-domains include measures related to Global Functioning, Employment, School Participation, Legal Involvement, Living Situation, and Social Connectedness.

Overall, measures in the Functioning domain were rated as very useful, with a moderate collection burden:

- Average clinical utility: 4.22
- Average administrative utility: 4.08
- Average Collection Burden: 2.59

Each of the measures included in the Functioning domain are broken out by their sub-domains in the subsequent sections. Seven programs evaluated the utility and burden of measures in the Functioning domain.



### **Functioning Sub-Domain: Global Functioning**

Measures in the Global Functioning sub-domain enable program developers to determine how well consumers are managing their daily lives, and succeeding in the community.

The measure included in the general functioning domain was evaluated as having relatively high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 3.27
- Average Administrative Utility: 3.59
- Average Collection Burden: 2.86

Table 7 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that only three early intervention program (Maryland RAISE Connection, NAVIGATE, and EDAPT/SacEDAPT) provided quantitative evaluations of the utility and burden of the measures in this domain.

## Table 7: Utility and Burden Evaluation of the Measures in the Global FunctioningSub-Domain

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Sub-Domain: Global Functioning							
How do you spend your time during the day?	GF-R, and CSFRA	5	5	2			
I'm hopeful about the future	Maryland Assessment of Recovery Scale	4	4	2			
I believe I make good choices in my life	Maryland Assessment of Recovery Scale	3	4	2			
I am able to set my own goals in life	Maryland Assessment of Recovery Scale	3	4	2			
When I have a relapse, I am sure that I can get back on track	Maryland Assessment of Recovery Scale	3	4	2			
LEGEND							
Least burdensome and/or most useful Greatest burden and/or least useful							
Intermediate burden and/or usefulness N/A							



					Table 7 continued				
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
I am confident that I can make positive changes in my life	Maryland Assessment of Recovery Scale	4	4	2					
I feel accepted as who I am	Maryland Assessment of Recovery Scale	3	4	2					
I believe that I am a strong person	Maryland Assessment of Recovery Scale	4	4	2					
I feel good about myself even when others look down on my illness	Maryland Assessment of Recovery Scale	3	4	2					
I can have a fulfilling and satisfying life	Maryland Assessment of Recovery Scale	4	4	2					
I am optimistic that I can solve problems that I will face in the future	Maryland Assessment of Recovery Scale	3	4	2					
I can make changes in my life even though I have a behavioral health issue	Maryland Assessment of Recovery Scale	3	4	2					
I am responsible for making changes in my life	Maryland Assessment of Recovery Scale	4	4	2					
Intrapsychic Foundations — Sense of Purpose	Heinrichs Quality of Life Scale	3	3	4					
Intrapsychic Foundations — Motivation	Heinrichs Quality of Life Scale	3	3	4					
Intrapsychic Foundations — Curiosity	Heinrichs Quality of Life Scale	3	3	4					
LEGEND									
Least burg	LEGEND Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A								

Table 7 continued

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Intrapsychic Foundations — Anhedonia (inability to feel pleasure)	Heinrichs Quality of Life Scale	3	3	4				
Intrapsychic Foundations — Aimless Activity	Heinrichs Quality of Life Scale	3	3	4				
Intrapsychic Foundations — Empathy	Heinrichs Quality of Life Scale	3	3	4				
Intrapsychic Foundations — Emotional Interaction	Heinrichs Quality of Life Scale	3	3	4				
Commonplace Objects	Heinrichs Quality of Life Scale	3	3	4				
Commonplace Activities	Heinrichs Quality of Life Scale	3	3	4				
LEGEND								
Least burdensome and/or most useful Greatest burden and/or least useful								
	ate burden and/o	or usefulne	ess	N/A				

### **Functioning Sub-Domain: Employment**

The ability to secure and sustain employment is a critical indicator of functioning, because it demonstrates a consumer's ability to pursue and achieve major life goals. Each of the seven program developers interviewed indicated employment as one of the most important domains to include when establishing a framework of performance measures.

The measures included in the employment domain were evaluated as having high clinical and administrative utility, with a relatively low-to-moderate data collection burden:

- Average Clinical Utility: 4.25
- Average Administrative Utility: 4.30
- Average Collection Burden: 2.82

Highlighting its importance, the employment sub-domain boasts the highest number of indicators out of all domains evaluated in this report. Thirty-one employment measures were identified as being implemented by the early intervention programs interviewed for this report. Definitional issues can be a problem with measures in this sub-domain. Measures and instruments used to assess outcomes in the employment sub-domain should be clear about what types of work are considered "employment" (e.g., competitive employment, including full time and part time, and the number of hours for each; volunteer

work; etc.), and the timeframes for a valid positive response (e.g., if a person held a job for two weeks between evaluations, this likely would not be considered a positive response for "currently employed"). Yale STEP relies on the U.S. Department of Labor standards to classify employment types.

Table 8 lists the measures used by early intervention programs to assess performance in the employment sub-domain. Four early intervention programs (EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in the employment sub-domain.

# Table 8: Utility and Burden Evaluation of the Measures in the EmploymentSub-Domain



Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
Functioning Sub-Domain: Employment										
Primary Role (work, volunteer, school, homemaker)	CSFRA	5	5	3						
If currently working, where do you work? What are your job responsibilities?	GF-R, and CSFRA	4.5	4.5	2.5	Collected by Maryland RAISE Connection Program, EDAPT					
If currently working, how many hours per week do you work?	GF-R, and CSFRA	4	4	2	Collected by Maryland RAISE Connection Program, EDAPT					
If currently working, what is the length of time you have spent at your current job?	GF-R, and CSFRA	4	4	2	Collected by Maryland RAISE Connection Program, EDAPT					
If not currently working, what are your current goals (for a job)?	CSFRA	5	5	3						
Are there any challenges or barriers that are preventing you from reaching your goal?	CSFRA	5	5	3						
Have you met with our supported employment specialist?	CSFRA	5	5	3						
LEGEND										
Least b	Least burdensome and/or most useful Greatest burden and/or least useful									

N/A

Intermediate burden and/or usefulness

Table 8 continue									
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
Any changes in job status during the assessment interval?	GF-R, and CSFRA	4	4	2	Collected by Maryland RAISE Connection Program, EDAPT				
Number of jobs held during follow-up period	CSFRA	5	5	3					
Any need for assistance/regular supervision at work? How often do you need extra help? Are there any other tasks that you are not able to do alone?	GF-R, and CSFRA	4	4.5	2	Collected by Maryland RAISE Connection Program, EDAPT				
If you have trouble keeping up with your work, and if you fall behind are you able to catch up?	GF-R, and CSFRA	4	4	2	Collected by Maryland RAISE Connection Program, EDAPT				
Feedback on work performance (positive and negative)	GF-R, and CSFRA	4	4.5	2.5	Collected by Maryland RAISE Connection Program, EDAPT				
If a homemaker, what are your responsibilities?	GF-R, and CSFRA	4	4	2	Collected by Maryland RAISE Connection Program, EDAPT				
If a homemaker, how long have you been in charge of the home?	GF-R, and CSFRA	5	5	3					
If a homemaker, how many hours per week do you spend on your responsibilities?	GF-R, and CSFRA	5	5	3					
If a homemaker, are you able to keep up with the demands?	GF-R, and CSFRA	3.5	4	2	Collected by Maryland RAISE Connection Program, EDAPT				
LEGEND									
	Least burdensome and/or most useful Greatest burden and/or least useful								
Interme	diate burden	and/or use	efulness	1	N/A				

Table 8 continu										
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
If a homemaker, what type of feedback do you receive on your performance?	GF-R, and CSFRA	3.5	4	2	Collected by Maryland RAISE Connection Program, EDAPT					
Are you currently volunteering? If yes, what are your responsibilities?	CSFRA	5	5	3						
How many hours per week do you volunteer?	CSFRA	5	5	3						
How long have you been at your volunteer job? Is this a new volunteer job?	CSFRA	5	5	3						
Have you had any recent changes in your volunteer status? Number of volunteer jobs held during follow-up period.	CSFRA	5	5	3						
Do you usually need assistance or regular supervision when volunteering? How often do you need extra help? Are there any tasks that you are not able to do alone?	CSFRA	5	5	3						
Do you ever have trouble keeping up? Are you able to catch up if you fall behind in your volunteer job?	CSFRA	5	5	3						
LEGEND	LEGEND									
	Least burdensome and/or most useful Greatest burden and/or least useful									
Interme	Intermediate burden and/or usefulness N/A									

					Table & continued					
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
Have you received any comments (positive or negative) or formal reviews regarding your volunteer performance? Have others pointed out things you have done well or poorly?	CSFRA	5	5	3						
Main source of income	CSFRA	5	5	3						
Do you receive any benefits? If yes, which (SSI, SSDI, CalFresh, CA Lifeline/Phone, Other)?	CSFRA	5	5	3						
Disability Benefits Status	EASA Outcome Review Form	5	5	2						
Yearly income	BeST Practices Outcome Review Form	N/A	3	3						
Current employment status	BeST Practices Outcome Review Form	5	5	3						
Percentage in competitive employment at one/ two/three years	Admin. Records	5	3	2	A clear definition of work and the timeframe for the information are needed.					
How many weeks did the client work in the last quarter?	EASA Intake Form	2	2	4	Potentially a useful measure, but is not used by the EASA program very often.					
LEGEND	LEGEND									
	LEGEND Least burdensome and/or most useful Intermediate burden and/or usefulness N/A									

					Table 8 continued
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments
Employment status (e.g., full time, part time, etc.) in the last three months/this quarter	EASA Intake Form, EASA Outcome Review Form	5	5	5	This measure is used a lot. The program also has asked whether work was disrupted due to symptoms, which had been a useful measure.
Employment type (e.g., competitive, supportive, sheltered, etc.)	EASA Intake Form, EASA Outcome Review Form	5	5	3	Definitional issues occasionally arise.
Current vocational rehab status	EASA Outcome Review Form	3	5	2	This item is primarily geared to help EASA develop their state-level relationship with vocational rehab and lay groundwork for program development.
Did symptoms impact employment situation in the last three moths/this quarter?	EASA Outcome Review Form. EASA Intake Form	5	5	3.5	Definitional issues occasionally arise.
Instrumental Role — Occupational	Heinrichs Quality of Life Scale	3	3	4	
Instrumental Role — Work Functioning	Heinrichs Quality of Life Scale	3	3	4	
Instrumental Role — Work Level	Heinrichs Quality of Life Scale	3	3	4	
Instrumental Role — Work Satisfaction	Heinrichs Quality of Life Scale	3	3	4	
LEGEND					
	urdensome a	nd/or most	useful		Greatest burden and/or east useful
Interme	diate burden	and/or use	fulness	1	N/A

## **Functioning Sub-Domain: School Participation**

Similar to employment, school participation is a critical factor in understanding how well consumers are succeeding at meeting their life goals and participating in the community. Each of the seven program respondents interviewed identified school participation as one of the most important areas to include when establishing a framework of performance measures.

The measures included in the school participation sub-domain were evaluated as having high clinical and administrative utility, with a relatively low-to-moderate data collection burden:

- Average Clinical Utility: 4.66
- Average Administrative Utility: 4.41
- Average Collection Burden: 2.47

Table 9 lists the measures used by early intervention programs to assess performance in the school participation sub-domain. Five early intervention programs (EDAPT/SacEDAPT, Maryland RAISE Connection Program, BeST Center, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in the education domain.

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
Functioning Sub-Dom	Functioning Sub-Domain: School Participation									
If not working, volunteering, or in school, what are your current goals (for a job or school)?	CSFRA	5	5	3						
Are there any challenges or barriers that are preventing you from reaching this goal?	CSFRA	5	5	3						
Have you met with the program's supported education specialist?	CSFRA	5	5	3						
LEGEND	LEGEND									
Least burdensome and/or most useful Greatest burden and/or least useful										
Intermedia	te burden and/o	or usefulne	ess	N/A						

# Table 9: Utility and Burden Evaluation of the Measures in the School ParticipationSub-Domain

					Table 9 continued		
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Are you currently attending school? If yes, name of school.	CSFRA	5	5	3			
What type of school do you attend?	GF-R, CSFRA, EASA Outcome Review Form, EASA Intake Form	5	5	2.5			
How long have you been at this school? Are you attending a new school (changed in past six months)?	GF-R, and CSFRA	5	5	3			
Have you had any recent changes in your school placement? Number of schools attended during the follow-up period.	GF-R, and CSFRA	5	5	3			
Do you require extra help/ accommodations (e.g., tutoring, test accommodations)?	GF-R, CSFRA, EASA Outcome Review Form, EASA Intake Form	4.5	4.5	3			
Any trouble keeping up with coursework? If you fall behind, are you able to catch up?	GF-R, and CSFRA	5	5	3			
How are your grades? Are you failing any classes?	GF-R, and CSFRA	5	5	3			
Graduation rate: are you on track to graduate?	CSFRA	5	5	3			
Do you have an IEP or 504 Plan? Are you in special education classes or other non-general education classes?	GF-R, CSFRA, EASA Outcome Review Form, EASA Intake Form*	5	5	3			
LEGEND							
Least burdensome and/or most useful Greatest burden and/or least useful							
Intermedia	ate burden and/o	or usefulne	ess	N/A			

Measure								
weasure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Highest grade level completed	BeST Practices Outcome Review Form	5	3	3				
Current education status	BeST Practices Outcome Review Form	5	5	3				
Education (percentage participating in education) at one year, two years, and three years	Admin. Records	5	3.2	2	There needs to be a clear definition of participation, such as enrolled in at least one course and attended a full semester, or still attending if a semester is not over.			
Last grade completed	EASA Outcome Review Form, EASA Intake Form	5	N/A	3	There have been accuracy issues with this measure (i.e., reverting grade levels when clearly that is not possible).			
Educational milestones completed (e.g., degree status)	EASA Outcome Review Form	4	N/A	4	Similar to "Last grade completed," there are definitional issues with data collection. Finishing 12th grade is not the same as graduating; currently the program does not track modified diplomas versus regular diplomas.			
School status (e.g., full time, part time, etc.)	EASA Outcome Review Form, EASA Intake Form	5	5	2				
Does the client want to go to school (now or in the future)?	EASA Outcome Review Form, EASA Intake Form	4	4	3	This is a subjective measure; it is not clear that clinician report corresponds to participant perception.			
LEGEND								
Least burdensome and/or most useful Greatest burden and/or least useful								
Intermedia	te burden and/c	or usefulne	ess	N/A	<b>N</b>			

Table 9 continu									
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
Type of school attending	EASA Outcome Review Form, GFS — Social and Role	4	4.5	1.5	Measure collected by EASA and Maryland RAISE Connection Program				
If currently attending school, have you ever been in special education classes or other non-general education classes?	GFS — Social and Role	4	4	1					
If currently attending school, how long have you been at this school? Have you had any recent changes in your school placement?	GFS — Social and Role	3	3	1					
If currently attending school, do you receive any extra help or accommodations in your classes? Do you receive tutoring or extra help in school or after school? Do you receive extra time to take tests, or are you able to leave the classroom to take tests in a quiet place?	GFS — Social and Role, EASA Outcome Review Form	4	4.5	2					
If currently attending school, do you have trouble keeping up with your coursework? Are you able to catch up if you fall behind?	GFS — Social and Role	4	4	1					
How are your grades? Are you failing any classes?	GFS — Social and Role	4	4	1					
Did symptoms impact school situation in the last three months/this quarter?	EASA Outcome Review Form	4	4	3					
LEGEND	LEGEND								
	Least burdensome and/or most useful Greatest burden and/or								
Intermedia	ate burden and/c	or usefulne	ess	lea	st useful A				

### **Functioning Sub-Domain: Legal Involvement**

The Legal Involvement sub-domain enables program developers to track consumers' interactions with law enforcement, including frequency of contact, and whether these interactions were a direct result of symptoms or substance use. These measures allow program developers to identify reasons for legal involvement, and make any necessary adjustments to the treatment program.

Measures included in the Legal Involvement sub-domain were evaluated as having high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 4.25
- Average Administrative Utility: 3.00
- Average Collection Burden: 2.75

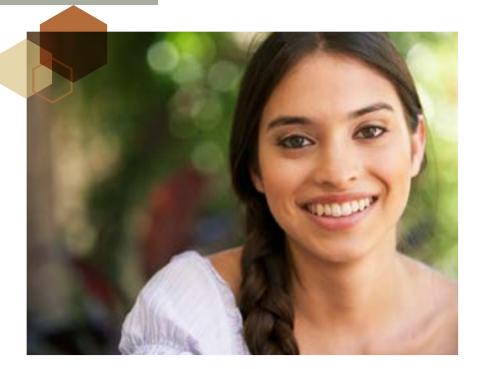


Table 10 lists the questions used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (Calgary EPTS, EASA, EDAPT/ SacEDAPT, and Ohio BeST Center's FEP (FIRST) program) provided quantitative evaluations of the utility and burden of the measures in this domain.

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
Functioning Sub-Dom	Functioning Sub-Domain: Legal Involvement									
Status of Legal Involvement	EASA Outcome Review Form, EASA Intake Form, Health Records	4.3	5	2.7	Requires knowledge of a person's situation to complete. Collected by EASA, Calgary EPTS, Ohio BeST Center's FEP (FIRST) Program, and EDAPT					
If the client had legal involvement, name of facility, placement code, date of admission, and date of discharge	CSFRA	5	5	2						
If arrested, what was the client charged with?	BeST Practices Outcome Review Form	4	1	3						
Was legal involvement related directly to psychiatric symptoms or substance use?	BeST Practices Outcome Review Form, EASA Outcome Review Form, EASA Intake Form	3.3	1.7	3	EASA has not really used this measure; it is somewhat subjective and would require additional data to interpret.					
LEGEND										
Legend Least burdensome and/or most useful least useful Intermediate burden and/or usefulness N/A										

Table 10: Utility and Burden Evaluation of the Measures in the Legal InvolvementSub-Domain



## Functioning Sub-Domain: Living Situation/Homelessness

Measures in the Living Situation/Homelessness sub-domain enable program developers to determine how well the consumer's basic needs are being met, with an emphasis on housing and income adequacy. These indicators also enable programs to provide services and supports as needed to improve or sustain housing for consumers enrolled in services.

Measures included in the Living Situation/Homelessness sub-domain were evaluated as having high clinical and administrative utility, with a very low collection burden:

- Average Clinical Utility: 4.92
- Average Administrative Utility: 4.85
- Average Collection Burden: 1.23

Table 11 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (EASA, Calgary EPTS, EDAPT/ SacEDAPT, and Ohio BeST Center's FEP (FIRST) program) provided quantitative evaluations of the utility and burden of the measures in this sub-domain.

### Sub-Domain Measure Source Clinical Utility Administrative Utility Collection Burden Comment

Table 11: Utility and Burden Evaluation of the Measures in the Living Situation

Measure	Source	Utility	Administrative Utility	Burden	Comments				
Functioning Sub-Domain: Living Situation									
Current Living Situation	CSFRA, BeST Practices Outcome Review Form, Admission/ Discharge Tracking Form, EASA Referral Form, EASA Outcome Review Form, EASA Intake Form	4.8	4.5	1.8	Measure collected by Calgary EPTS, EDAPT, Ohio BeST, and EASA				
Does anyone live with you?	CSFRA	5	5	1					
LEGEND									
Least burc	lensome and/or	most usef	ul 🗾	Greates least us	t burden and/or eful				
	ate burden and/o	or usefulne	SS	N/A					



Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Are you dealing with any challenges in your current living situation?	CSFRA	5	5	1				
Are you at risk of losing your current housing situation?	CSFRA	5	5	1				
Have you had any changes in your living situation since your last assessment?	CSFRA	5	5	1				
Out of home placement	CSFRA	5	5	1				
Do you pay for your housing from wages earned? If no, who pays for your housing?	CSFRA	5	5	1				
Do you have any other bills or expenses that you pay per month, such as groceries/food, phone bills, utility bills, tuition, transportation, etc.? If so, how do you pay for them?	CSFRA	5	5	1				
Are you having any difficulty paying your bills or paying for the things you need? If yes, has anyone at the program worked with you to address these challenges? Would you like help with them?	CSFRA	5	5	1				
LEGEND								
Least burdensome and/or most useful     Greatest burden and/or     least useful     Intermediate burden and/or usefulness     N/A								

## **Functioning Sub-Domain: Social Connectedness**

Measures in the Social Connectedness sub-domain enable program developers to

determine how well consumers are engaging in meaningful activities in their own communities. Social connectedness is included as one of SAMHSA's identified National Outcome Measures (NOMs). One of the primary goals of early intervention programs is to minimize disability for persons experiencing initial episodes of SMI, and to help them build and maintain strong social relationships.

Measures included in the Social Connectedness sub-domain were evaluated as having high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 4.19
- Average Administrative Utility: 3.73
- Average Collection Burden: 2.67

Table 12 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (NAVIGATE, Maryland RAISE Connection Program, EDAPT/SacEDAPT, and Ohio BeST Center's FEP (FIRST) program) provided quantitative evaluations of the utility and burden of the measures in this sub-domain.

# Table 12: Utility and Burden Evaluation of the Measures in the SocialConnectedness Sub-Domain



Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
Functioning Sub-Domain: Social Connectedness									
Tell me about your social life. Who do you spend time with?	GF-S	4.5	4	2	Collected by EDAPT and the Maryland RAISE Connection Program				
Are these friends casual or close friends? If only casual, are they school or work friends only?	GF-S, and CSFRA	4.5	4	2	Collected by EDAPT and the Maryland RAISE Connection Program				
How often do you see friends? Do you see them outside of work/ school? When was the last time you saw one of your friends outside work/school?	GF-S, and CSFRA	4.5	4	2	Collected by EDAPT and the Maryland RAISE Connection Program				
LEGEND									
Least burdensome and/or most useful Greatest burden and/or least useful N/A									
			11000	11//	<b>`</b>				

Source GF-S, and CSFRA GF-S, and CSFRA	Clinical Utility 4.5	Administrative Utility 4	Collection Burden 2	Comments Collected by EDAPT and the Maryland RAISE Connection Program			
CSFRA		4	2	and the Maryland RAISE			
	4 -						
	4.5	5	2	Collected by EDAPT and the Maryland RAISE Connection Program			
GF-S, and CSFRA	4.5	3.5	2	Collected by EDAPT and the Maryland RAISE Connection Program			
GF-S, and CSFRA	4.5	4	2	Collected by EDAPT and the Maryland RAISE Connection Program			
GF-S, and CSFRA	5	5	3				
GF-S, and CSFRA	5	5	3				
GF-S, and CSFRA	5	5	3				
GFS-Social	4	3	1				
LEGEND  Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A							
	SFRA F-S, and SFRA F-S, and SFRA F-S, and SFRA F-S, and SFRA SFRA some and/o	SFRA F-S, and 5 SFRA 5 F-S, and 5 SFRA 5 F-S, and 5 SFRA 5 SFRA 4 some and/or most us	SFRA   F-S, and   SFRA   5   Some and/or most useful	SFRA   F-S, and   SFRA   5   5   SFRA   5   5   3   F-S, and   5   5   SFRA   5   5   3   F-S, and   5   5   3   FS-Social   4   3   1			

Table 12 cont								
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Client relationship with family/ significant others	BeST Practices Outcome Review Form	5	5	3	Add various levels to monitor change over time (e.g., does not get along with family — gets along with family all of the time)			
Is there a family member/ significant other whom the client would want to be more involved in treatment?	BeST Practices Outcome Review Form	5	1	3				
Interpersonal Relations — Household	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Friends	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Acquaintances	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Social Activity	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Social Network	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Withdrawal	Heinrichs Quality of Life Scale	3	3	4				
Interpersonal Relations — Sociosexual	Heinrichs Quality of Life Scale	3	3	4				
LEGEND	LEGEND							

Least burdensome and/or most useful

Intermediate burden and/or usefulness

Greatest burden and/or least useful N/A

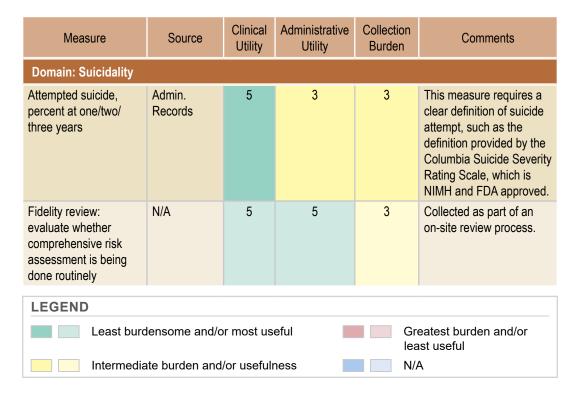
## **DOMAIN: SUICIDALITY**

The Suicidality domain enables staff to understand which consumers are at risk for suicidal ideation so they can modify services to reduce the risk of suicide in consumers, and identify trends in suicidal thoughts and triggers.

Measures included in the Suicidality domain were evaluated as having high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 4.65
- Average Administrative Utility: 4.02
- Average Collection Burden: 1.23

Table 13 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (NAVIGATE, Maryland RAISE Connection Program, EASA, and Calgary EPTS) provided quantitative evaluations of the utility and burden of the measures in this domain. While these four programs provided feedback on individual measures of suicidality, other programs evaluated overall instruments that collect information about suicidality (e.g., the Columbia Suicide Severity Rating Scale), and did not rate the measures individually. Because of this approach, not all measures are included in table 12 below. A separate discussion about instruments is included in the section *Instruments Used to Collect Performance Measures*, beginning on page 62 of this report.



### Table 13: Utility and Burden Evaluation of the Measures in the Suicidality Domain

Table 13 continue							
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Demographic nformation (age, sex, education, race, religion, living parents, marital status, who client lives with)	Harkavy- Asnis Suicide Scale	4	5	1	Age and religion are demographic areas that can be very important clinically. Because we work with schizophrenia, age of onset of symptoms is key. Also, due to the nature of common delusions or hallucinations related to religion, it is important to know what part religion plays in the life of the client (i.e., if it is important and a major part of their life, if discussion of this should be avoided due to delusional content, etc.).		
Do you know what suicide is? Define in own words.	Harkavy- Asnis Suicide Scale	4	2	1			
Have you thought about killing yourself but did not actually try?	Harkavy- Asnis Suicide Scale	5	3	1			
If you have thought about killing yourself but did not actually try, have those thoughts persisted for at least seven days in a row?	Harkavy- Asnis Suicide Scale	5	4	1			
If you have thought about killing yourself but did not actually try, how old were you when you had these thoughts? List each age.	Harkavy- Asnis Suicide Scale	3	2	1			
If you have thought about killing yourself but did not actually try, did you have a plan? If yes, what were you going to do?	Harkavy- Asnis Suicide Scale	5	4	1			
LEGEND							
Least burd	lensome and/o	r most us	eful	-	eatest burden and/or ast useful		
Intermediate burden and/or usefulness N/A							

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments
lave you thought bout killing yourself in he past week?	Harkavy- Asnis Suicide Scale	5	4	1	
f you have thought bout killing yourself in the past week, have these thoughts hersisted for seven lays in a row?	Harkavy- Asnis Suicide Scale	5	5	1	
f you have thought bout killing yourself in he past week, do you ave a plan? If yes, what specifically are ou thinking of doing?	Harkavy- Asnis Suicide Scale	5	4	1	
lave you ever tried to ill yourself?	Harkavy- Asnis Suicide Scale	5	4	1	
f you have tried to kill ourself, how many mes?	Harkavy- Asnis Suicide Scale	5	4	1	
f you have tried to ill yourself, how pecifically did you try o kill yourself?	Harkavy- Asnis Suicide Scale	4	4	1	
f you have tried to kill ourself, at what age?	Harkavy- Asnis Suicide Scale	5	4	1	
f you have tried to kill ourself, how come ou tried to kill yourself please be specific)	Harkavy- Asnis Suicide Scale	4	4	1	
f you have tried o kill yourself, did ou require medical reatment after you ried to kill yourself? f yes, what kind and where?	Harkavy- Asnis Suicide Scale	5	4	1	
f you have tried to kill ourself, did you tell nyone before?	Harkavy- Asnis Suicide Scale	5	4	1	
LEGEND					
Least burg	densome and/o	r most us	eful		eatest burden and/or ast useful

					Table 13 continue	
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments	
If you have tried to kill yourself, did you tell anyone after?	Harkavy- Asnis Suicide Scale	5	4	1		
If you have tried to kill yourself, did you want to die?	Harkavy- Asnis Suicide Scale	5	5	1		
If you have tried to kill yourself, did you expect to die?	Harkavy- Asnis Suicide Scale	5	5	1		
If you have tried to kill yourself, were you in psychiatric treatment when you tried?	Harkavy- Asnis Suicide Scale	4	4	1		
If you have tried to kill yourself, did you start psychiatric treatment within the month after you tried to kill yourself?	Harkavy- Asnis Suicide Scale	5	5	1		
Have family members talked about killing themselves? If yes, who and relationship?	Harkavy- Asnis Suicide Scale	5	5	1		
Has anyone in your family tried to kill him/ herself? If yes, who and relationship?	Harkavy- Asnis Suicide Scale	5	5	1		
Has anyone in your family killed him/ herself? If yes, who and relationship?	Harkavy- Asnis Suicide Scale	5	5	1		
Did you know anybody who has tried to kill him/herself? If yes, who and relationship?	Harkavy- Asnis Suicide Scale	5	5	1		
Do you know anybody who has killed him/ herself? If yes, who and relationship?	Harkavy- Asnis Suicide Scale	5	5	1		
LEGEND						
Least burdensome and/or most useful Greatest burden and/or least useful						

Information Guide: Use of Performance Measures in Early Intervention Programs

Intermediate burden and/or usefulness

N/A

					Table 13 continued		
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
Have you ever seen an individual, such as a counselor, psychiatrist, or social worker for any emotional problems you were having? If yes, please list the profession of the person you were seeing, how old you were, and how long you were seeing that person. Include profession, dates, length of treatment, and age when started.	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you thought that you would be better off dead?	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you dreamed about death?	Harkavy- Asnis Suicide Scale	4	4	1			
How often have you had ideas about killing yourself?	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you thought the world would be better off without you?	Harkavy- Asnis Suicide Scale	4	4	1			
How often have you thought about death and dying?	Harkavy- Asnis Suicide Scale	4	4	1			
LEGEND							
LEGEND Least burdensome and/or most useful Intermediate burden and/or usefulness N/A							

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments		
How often have you smoked marijuana?	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you been in high places and felt like jumping?	Harkavy- Asnis Suicide Scale	4	4	1			
How often have you thought about ways to kill yourself?	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you taken drugs other than marijuana or prescription drugs?	Harkavy- Asnis Suicide Scale	5	4	1			
How often have you gotten so discouraged that you thought about ending your life?	Harkavy- Asnis Suicide Scale	4	4	1			
How often have you felt like running into traffic?	Harkavy- Asnis Suicide Scale	4	4	1			
Have you felt that life wasn't worth living? Did you ever feel like ending it all? What did you think you might do? Did you actually try?	Calgary Depression Scale	3	2	3			
LEGEND							
LEGEND Least burdensome and/or most useful Intermediate burden and/or usefulness N/A							

## **DOMAIN: PSYCHIATRIC HOSPITALIZATION**

Measures in the Psychiatric Hospitalization domain allows early intervention programs to

determine how well they are doing at helping individuals avoid psychiatric hospitalization, including reducing readmissions and decreasing lengths of stay. Keeping consumers out of psychiatric hospitals should indicate that they are doing well symptomatically and also produces cost savings to funders.

Measures included in Psychiatric Hospitalization domain were evaluated as having high clinical and administrative utility, with a moderate collection burden; however, the burden score of this domain may be misleading. One of the programs evaluating measures in this domain receives automatic updates from the hospitals in the county whenever one of their consumers presents for treatment. It is likely that other programs will have to collaborate with state agencies to access Medicaid data or SMHA data on hospitalization, or work directly with local hospitals to obtain these data:

- Average Clinical Utility: 4.30
- Average Administrative Utility: 4.22
- Average Collection Burden: 2.30

Table 14 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in this domain.

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments					
Domain: Psychiatric Hospitalization										
Since your last assessment, have you been admitted to the hospital because of mental health difficulties?	CSFRA	4	4	2	Program also has access to these data from the county.					
Number of hospital admissions (>24 hours/ put on hold)	CSFRA	4	4	2						
Name of hospital/ crisis agency/partial treatment facility	CSFRA	4	4	2						
LEGEND										
Least burg	lensome an	d/or most	useful		Greatest burden and/or least useful					
Intermedia	te burden a	and/or use	fulness		N/A					

# Table 14: Utility and Burden Evaluation of the Measures in the Psychiatric Hospitalization Domain

					Table 14 continued
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments
Still in placement (at hospital, residential crisis facility, or partial treatment facility)?	CSFRA	4	4	2	
Length of stay	CSFRA, BeST Practices Outcome Review Form	4.5	4.5	2.5	Measure collected by EDAPT and Ohio BeST Center's FEP (FIRST) Program
Reason for admission (at hospital, residential crisis facility, or partial treatment facility)	CSFRA	4	4	2	
Since last assessment, have you been placed in a residential (i.e., overnight) facility?	CSFRA	4	4	2	
Placement code	CSFRA	4	4	2	
Have you participated in a daily treatment alternative to hospitalization (e.g., partial hospitalization, day treatment)?	CSFRA	4	4	2	
Hospitalization type (including none, crisis stabilization, private psychiatric inpatient unit at hospital, state psychiatric inpatient unit, ER visit, etc.)?	BeST Practices Outcome Review Form	5	5	3	
Percentage of patients who have at least one admission to a hospital inpatient psychiatric unit by one year/two years/three years from admission to program	Admin. Records	5	5	2	This does not include admissions before program entry.
Since last assessment, have you gone to the ER or hospital for other medical reasons?	CSFRA	4	4	2	
LEGEND					
Least burd	ensome an	d/or most	useful		Greatest burden and/or least useful
Intermedia	te burden a	and/or use	fulness		N/A

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Any overnight treatment related to psychiatric symptoms?	EASA Outcome Review Form, EASA intake Form, CSFRA	4.7	4.7	2.7	Measure collected by EASA (two different forms) and EDAPT			
Voluntary status	EASA Outcome Review Form, EASA intake Form	4	4	3				
Does the client have advance directives for mental health treatment? Would they like to create Advance Directives?	BeST Practices Outcome Review Form	2.5	2	3				
LECEND								
LEGEND								
Least burdensome and/or most useful Greatest burden and/or least useful								

### DOMAIN: USE OF EMERGENCY ROOMS

Intermediate burden and/or usefulness

Measures in the Use of Emergency Rooms domain enable program developers to determine whether or not consumers are using crisis services to manage physical or behavioral health symptoms between program assessments.

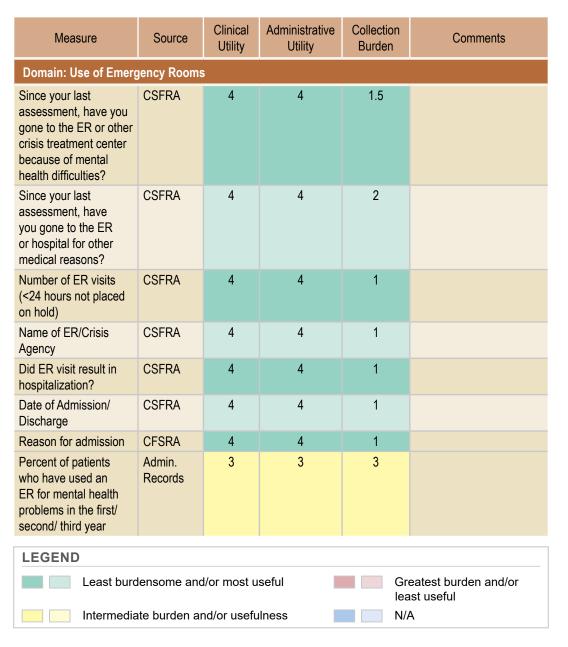
N/A

Measures included in Use of Emergency Rooms domain were evaluated as having moderately high clinical and administrative utility, with a low collection burden; however, similar to the Psychiatric Hospitalization domain, the low burden score for in this domain may be misleading. One of the programs evaluating measures in this domain receives automatic updates from the hospitals in the county whenever one of their consumers presents for treatment. It is more likely that other programs will have to collaborate with other state agencies or local hospitals to obtain these data in a timely fashion.

- Average Clinical Utility: 3.88
- Average Administrative Utility: 3.88
- Average Collection Burden: 1.44

Table 15 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that early intervention programs EDAPT/SacEDAPT and Calgary EPTS provided quantitative evaluations of the utility and burden of the measures in this domain.

Table 15: Utility and Burden Evaluation of the Measures in the Use of EmergencyRooms Domain





## DOMAIN: SUBSTANCE USE

Measures in the Substance Use domain enable program staff to identify and manage co-occurring substance use disorders. Measures included in Substance Use domain were evaluated as having moderately high clinical and administrative utility, with a lower than average collection burden:

- Average Clinical Utility: 3.67
- Average Administrative Utility: 3.71
- Average Collection Burden: 2.67

Table 16 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in this domain.

# Table 16: Utility and Burden Evaluation of the Measures in the SubstanceUse Domain

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
Domain: Substance Use									
Problems caused by alcohol/drug use? Has anyone expressed concerns about your use?	CSFRA, EASA Outcome Review Form, EASA Intake Form	3.7	3.8	3	Measure collected by EASA and EDAPT.				
Have you attended substance abuse management group? If not, why? Would you like to?	CSFRA	3	4	N/R					
Frequency of substance use (alcohol and other substances)	BeST Practices Outcome Review Form, EASA Outcome Review Form, and CSFRA	3.9	4.3	2.7	Measure collected by EASA and EDAPT. EASA does not differentiate between type of substance. Because of this it is a fairly imprecise measure.				
LEGEND									
Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A									

Table 16 continu								
Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
Type of substances used, including tobacco	BeST Practices Outcome Review Form	3	3	3				
Percentage with a substance use disorder diagnosis on admission/ one year/two years/ three years	Admin. Records	5	5	1	This is part of routine diagnostic information that may be relevant for insurance reimbursement.			
LEGEND								
Least burdensome and/or most useful Greatest burden and/or least useful								
Intermediate	burden and/or use	efulness		N/A				

### DOMAIN: PRESCRIPTION ADHERENCE AND SIDE EFFECTS

Measures in the Prescription Adherence and Side Effects domain enable program staff to determine how well consumers are complying with medication guidelines, reasons for non-adherence, and to assess any adverse side effects from taking the prescriptions. Measures in this domain can also be used to assess the consumers' insight and memory and to see how well they can reflect on their prescription usage.

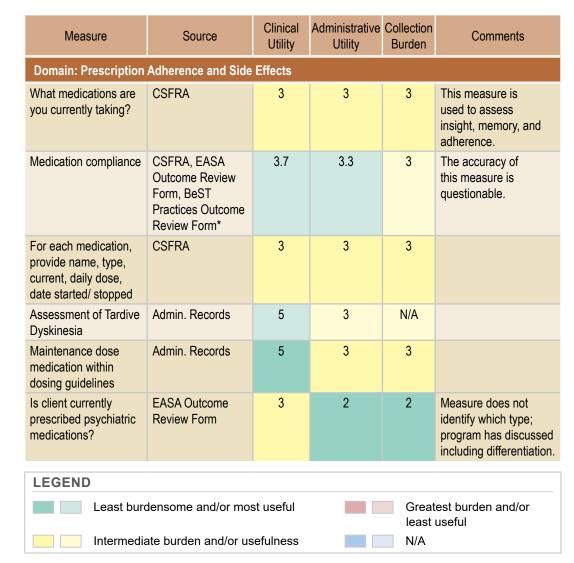
Measures included in the Prescription Adherence and Side Effects domain were evaluated as having moderate clinical and administrative utility, with moderate collection burden:

- Average Clinical Utility: 3.75
- Average Administrative Utility: 3.00
- Average Collection Burden: 3.00



Table 17 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in this domain.







## DOMAIN: PHYSICAL HEALTH

Measures in the Physical Health domain enable program developers to determine how well consumers evaluate their general health status and access primary care medical services. This domain also includes information about the insurance status of consumers, which enables early intervention programs to help ensure reimbursement for services.

Measures included in Physical Health domain were evaluated as having moderately high clinical and administrative utility, with a moderate collection burden:

- Average Clinical Utility: 4.50
- Average Administrative Utility: 3.47
- Average Collection Burden: 2.40

Of the measures included in this domain, the program developers interviewed for this report strongly recommend that others collect the following:

Status of health insurance

Table 18 lists the measures used by the early intervention programs interviewed for this report, along with their corresponding clinical and administrative utility and collection burden scores. Note that four early intervention programs (EDAPT/SacEDAPT, Ohio BeST Center's FEP (FIRST) program, Calgary EPTS, and EASA) provided quantitative evaluations of the utility and burden of the measures in this domain.

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments				
Domain: Physical Hea	lth								
Do you have concerns about your physical health or any ongoing medical problems?	CSFRA	4	4	2					
Does client have a primary care doctor?	CSFRA, BeST Practices Outcome Review Form, EASA Outcome Review Form	4.7	3.7	2.3	Measure collected by EDAPT, Ohio BeST Center's FEP (FIRST) Program, and EASA				
	Least burdensome and/or most useful       Greatest burden and/or least useful         Intermediate burden and/or usefulness       N/A								

#### Table 18: Utility and Burden Evaluation of the Measures in Physical Health Domain

Measure	Source	Clinical Utility	Administrative Utility	Collection Burden	Comments			
If client has a primary care physician, how many months since last contact?	EASA Outcome Review Form	5	2	3				
Is program in contact with primary care physician?	EASA Outcome Review Form	4	4	2				
Do you have a dentist?	CSFRA	4	4	2				
Status of insurance (including name of provider)	CSFRA, BeST Practices Outcome Review Form, EASA Outcome Review Form	5	3.7	3	Measure collected by Ohio BeST Center's FEP (FIRST) Program and EASA			
Have there been any changes in your insurance?	CSFRA	4	4	2				
Medical services received (since last review)	BeST Practices Outcome Review Form	3	1	3				
Weight (percent with BMI <25 at one/two/ three years)	Admin. Records	5	3	2				
LEGEND								
Least burdensome and/or most useful     Greatest burden and/or     least useful     Intermediate burden and/or usefulness     N/A								

### **INSTRUMENTS USED TO COLLECT PERFORMANCE MEASURES**

A variety of instruments are used by each of the programs interviewed to collect performance measurement data. A key lesson indicated by all programs contributing to this report is instruments and measures should be simple to administer and collect. Instruments with ratings of 5 in both clinical and administrative utility are:

- Clinical Global Impressions Scale for Schizophrenia: collects information about symptoms associated with schizophrenia.
- Clinician-Rated Dimensions of Psychosis Symptoms Severity: collects information about symptoms associated with schizophrenia.
- Columbia Suicide Severity Rating Scale: allows assessment of suicide risk factors.
- · EASA Intake From: provides information about identification, intake and enrollment.

Instruments with the lowest collection burden ratings are:

- Clinical Global Impressions Scale for Schizophrenia (data collection burden = 2)
- Global Functioning Social and Role (data collection burden = 2.5)
- Columbia Suicide Severity Rating Scale (data collection burden = 2.5)

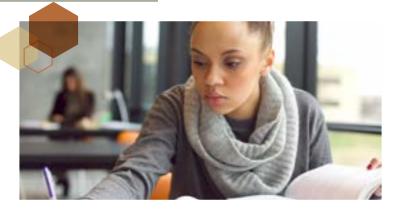
Table 19 outlines which instruments are used by which programs, for which domains they collect information about, their respective utility and burden ratings (when available), and any comments made in support or against the use of the instrument. (Note: some of these instruments are not included in the evaluation of individual measures in the domains sections above, as some programs only evaluated the utility and burden of instruments overall in assessing program performance.)

# Table 19: Utility and Burden Ratings for Data Collection Instruments Used by EarlyIntervention Programs

Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments	
Admission/ Follow-up/ Discharge Form	OnTrackNY	Employment School Participation Legal Involvement Living Situation Suicidality Psychiatric Hospitalization Use of ERs Substance Use Prescription Adherence and Side Effects	1.4	1.6	2		
Alcohol/ Drug Use Scales	Yale STEP	Substance Use	N/A	N/A	N/A	This instrument counts habits, and helps determine if use of substances equals abuse and dependence. Yale STEP estimates this will take clinicians 5 minutes to complete.	
LEGEND							
	LEGEND Least burdensome and/or most useful Least burden and/or usefulness Intermediate burden and/or usefulness N/A						



Instrument	Programs Using	Domains	Clinical	Admin.	Collection	Comments		
	Instrument		Utility	Utility	Burden			
Adult Needs and Strengths Assessment	PREP/BEAM	Suicidality Legal Involvement Employment School Participation Living Situation Substance Use Physical Health	4	5	4	Clinically important information if not collected elsewhere. This is required of California counties. It is long, but easy to rate, especially along with other assessments. Data are not quantified in a way that is easy for research purposes.		
ASRM	PREP/BEAM	Symptoms	3	4	3			
ASSIST	PREP/BEAM	Substance Use	2	3	3	Relies on accurate self-report. Having a score to discuss with a client could improve insight, but clinical utility depends on frequency of administration and timeliness of feedback. Dependent on reminders from evaluation team and tracking down clients.		
LEGEND								
	Least burdensome and/or most useful Greatest burden and/or least useful Intermediate burden and/or usefulness N/A							



			1			Table 19 continue			
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments			
BeST Practices Outcome Review Form	BeST Center	Legal Involvement Employment School Participation Living Situation Psychiatric Hospitalization Use of Emergency Rooms Social Connectedness Substance Use Prescription Adherence and Side Effects Physical Health	4.55	3.90	2.90				
Brief Negative Symptom Assessment Scale	Symptoms	Maryland RAISE Connection Program	5	4	1				
Calgary Depression Scale	Calgary EPTS Yale STEP BeST Center NAVIGATE	Improved Symptoms Suicidality	3	2	3	Yale STEP estimates this will take clinicians 5 minutes to complete. NAVIGATE is the only program to provide utility/burden ratings for this instrument.			
LEGEND									
Least		nd/or most useful and/or usefulness	5		Greatest bur least useful N/A	den and/or			

						Table 19 continued
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Cannabis Scale	Yale STEP	Substance Use	N/A	N/A	N/A	Includes information on historical use of cannabis, not just current use. Also asks about social isolation when using. It is a very helpful scale because it is a particular prominent issue for the population served by the Yale STEP program. Yale STEP estimates this will take clinicians 5 minutes to complete.
CGI-Schizophrenia	EDAPT/ SacEDAPT	Improved Symptoms	5	5	2	
Client Symptom and Functioning Reassessment	EDAPT/ SacEDAPT	Program Involvement Improved Symptoms Functioning Employment School Participation Living Situation Psychiatric Hospitalization ER Use Social Connectedness Substance Use Prescription Adherence and Side Effects Physical Health	4	3.42	2.99	Developed by EDAPT, and constantly updated based identification of new needs and requests for information.
LEGEND						
Least b	ourdensome a	nd/or most useful			Greatest bur least useful	den and/or
	ediate burden	and/or usefulness	;		N/A	

Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Clinician-Rated Dimensions of Psychosis Symptoms Severity Scale	BeST Center	Improved Symptoms	5	5	3	
Clinician-Version Clinical Global Impressions: Severity	NAVIGATE	Symptoms	3	2	1	
Columbia Suicide Severity Rating Scale	Yale STEP	Suicidality	5	5	2.5	Yale STEP estimates this will take clinicians 5 minutes to complete. The Columbia Suicide Severity Rating Scale (CSSRS) was the most recommended instrument by programs interviewed for this report.
EASA Education and Outreach Form	EASA	Identification, Intake, Enrollment	4	5	3	
EASA Intake Form	EASA	Identification, Intake, Enrollment Living Situation Employment School Participation Legal Involvement Program Involvement	5	5	3	
LEGEND						
Least I	ourdensome a	nd/or most useful			Greatest bur least useful	den and/or
Interm	ediate burden	and/or usefulness			N/A	

						Table 19 continue
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
EASA Outcome Review Form	EASA	Psychiatric Hospitalization Substance Use Prescription Adherence and Side Effects Physical Health Living Situation Employment School Participation Legal Involvement Program Involvement	4.24	3.64	2.96	
EASA Referral and Decision Form	EASA	Identification, Intake, Enrollment Living Situation	4	4	3	
El Suicide Risk Factor Checklist	PREP/BEAM	Suicidality	4	5	3	Used only when indicated clinically. A bit clunky, but useful and crucial. Takes training and a considerable time to administer. Standardized prompts would be useful. Cut-off scores make decision- making easier when determining risk. Provides treatment guidance and documentation for legal purposes.
LEGEND						
		nd/or most useful			Greatest bur least useful	den and/or
	ediate burden	and/or usefulness	;		N/A	

						Table 19 continued
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Four-Item Positive Symptom Rating Scale	Maryland RAISE Connection Program	Symptoms	5	4	1	This tool is very clinically useful to track the client's symptoms and duration. It is collected every three months, which allows the team to identify if specific features of schizophrenia have improved. This also helps administratively to track the effectiveness of interventions.
Global Functioning Social and Role Scales	PREP/BEAM Yale STEP Maryland RAISE Connection Program	Functioning Employment School Participation	2.9	3.2	1.8	Yale STEP estimates this will take clinicians 10 minutes to complete. PREP/ BEAM do not find the instrument very useful for clinical or research purposes.
Habits Inventory	Yale STEP	Substance Use	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 5 minutes to complete.
LEGEND						
		nd/or most useful and/or usefulness			Greatest bure least useful N/A	den and/or

Information Guide: Use of Performance Measures in Early Intervention Programs

Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Harkavy-Asnis Suicide Scale	Maryland RAISE Connection Program	Suicidality	5	4	1	This questionnaire is completed by the client at intake to assess the need for safety planning. This is part of the intake assessment to help in identifying any safety risks that may be present for the client.
Heinrichs Quality of Life Scale	Yale STEP NAVIGATE	Employment Social Connectedness	3	3	4	Yale STEP estimates this will take clinicians 20 minutes to complete. NAVIGATE is the only program to provide quantitative evaluations of this tool.
InterSePT Scale for Suicidal Thinking	PREP/BEAM	Suicidality	4	2	3	Used only when indicated clinically. A bit clunky, but useful and crucial. Takes training and a considerable time to administer. Standardized prompts would be useful. Cut-off scores make decision- making easier when determining risk. Provides treatment guidance and documentation for legal purposes.
Liverpool University Neuroleptic Side Effect Rating Scale	Yale STEP	Prescription Adherence and Side Effects	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 10 minutes to complete.

						Table 19 continued
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Maryland Assessment of Recovery Scale	Maryland RAISE Connection Program	Global Functioning	3	4	2	This is completed by the client upon intake and then annually. The reason that this scale is given is to assess if the client's ideas of themselves and the world have improved due to participation in treatment. This assessment has been somewhat difficult to administer due to the frequency with which clients are seen in the clinic. Most clients that have been with the program for one year are seen on a monthly basis, and if this measure is not administered at their monthly appointment, they will likely not complete it for another month. Some of the questions on the tool are also repetitive, which clients have reported to be annoying. Also, clients have reported that the language used in the tool (specifically the word "relapse") feels stigmatizing and
LEGEND						at times they have difficulty applying it to
Le	east burdensor	ne and/or most us	eful			themselves because it is more related to
		den and/or useful	ness			substance use than mental health. While
	reatest burden ast useful /∆	and/or				this tool can be used administratively to
						identify progress in the program, it does
						not provide much information clinically.

	i		Ì			Table 19 continue
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Medication Adherence Rating System	PREP/BEAM	Prescription Adherence and Side Effects	2	2	3	Not an ideal measure of medication adherence. Relies on self-report. Clinical utility depends on frequency of administration and timeliness of feedback. Dependent on reminders from evaluation team and tracking down clients.
MATRICS	Yale STEP	Functioning	N/A	N/A	N/A	
MIRECC GAF	OnTrackNY	Living Situation Functioning Education Employment	N/A	N/A	N/A	It is administered to clients at baseline and every three months. The tool is useful in making clinical and administrative decisions because it has an intuitive 0-100 scale.
Modified Overt Aggression Scale	Yale STEP	Improved Symptoms	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 5 minutes to complete.
PANSS	Yale STEP NAVIGATE	Improved Symptoms	3	2.5	3	Yale STEP estimates this will take clinicians 20 minutes to complete.
Pathways to Care	Yale STEP	Identification, Intake, and Enrollment	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 30 minutes to complete.
Premorbid Adjustment Scale	Yale STEP	Social Connectedness Functioning School Participation Employment	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 10 minutes to complete. It helps providers understand what clients' lives were like before they entered treatment, to help them establish a realistic baseline
LEGEND						
	hurdencomo o	nd/or most useful			Greatest burg	den and/or
					least useful	

N/A

Table 19 continued

Intermediate burden and/or usefulness

						Table 19 continued
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Prescription Medication Log	Yale STEP	Prescription Adherence and Side Effects	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 10 minutes to complete.
Quick Scale for the Assessment of Positive and Negative Symptoms	PREP/BEAM	Improved Symptoms	4	5	4	Useful for determining phase of treatment and providing feedback to the consumer, but requires intensive training and unclear reliability. Clunky; clients do not always like answering questions, but is useful for research purposes.
SCID	EDAPT/ SacEDAPT PREP/BEAM Yale STEP	Identification, Intake and Enrollment Suicidality Psychiatric Hospitalization Use of ERs	5	4	4	Yale STEP estimates this will take clinicians 45 minutes to complete. Scale is used to determine eligibility for treatment. Because of special funding streams in Connecticut (NIMH Research Funds through Yale STEP) and California (Prop 63), clinics in these states are able to bill time spent training to use and administer the SCID. Other programs, including the BeST Center, would like to use this or a similar tool to determine eligibility, but have been unable because of the expense and burden they tend to put on the providers.
LEGEND Least	burdensome a	nd/or most useful			Greatest burg	den and/or
Interm	ediate burden	and/or usefulness	3		N/A	

						Table 19 continued
Instrument	Programs Using Instrument	Domains	Clinical Utility	Admin. Utility	Collection Burden	Comments
Service Engagement Scale	Yale STEP	Identification, Intake, and Enrollment Prescription Adherence and Side Effects	N/A	N/A	N/A	Completed in clinical rounds, roughly 5-10 minutes to complete
Service Use and Resources Form (SURF)	Yale STEP	Program Involvement	N/A	N/A	N/A	Yale STEP estimates this will take clinicians 15 minutes to complete.
<u>SF-36</u> Questionnaire	Yale STEP		N/A	N/A	N/A	Yale STEP estimates this will take clinicians 15 minutes to complete.
SIPS Modified GAF Scale	Yale STEP PREP/BEAM	Identification, Intake and Enrollment	4	4.5	3	Yale STEP estimates this will take clinicians 45 minutes to complete. The SIPS is used to establish the presence of active psychosis and symptom onset. It is used by Yale STEP to help determine the duration of untreated psychosis. Yale STEP particularly likes this tool because it allows clinicians to be softer in their delivery of the questions, helping to put consumers at ease in the clinical setting.
Working Alliance Inventory	PREP/BEAM	Program Involvement	5	5	3	The combination of the client and clinician's working alliance is useful for treatment and research purposes.
LEGEND						
	ourdensome a	nd/or most useful			Greatest burd least useful	den and/or
	ediate burden	and/or usefulness	6		N/A	

#### Conclusion

It is crucial for early intervention CSC programs to monitor and evaluate performance from program inception to ensure quality of service delivery. Applying performance measurement at program onset allows programs to operationalize program goals, design services to meet these goals, and evaluate the degree to which the services are successful at achieving the goals. This information enables programs to make necessary adjustments to service delivery. It is also much less burdensome to establish this measurement framework at the beginning of a program, and make modifications to the framework later, rather than retrofitting a measurement system to an existing program and culture. Programs implementing data reporting requirements at initiation may have lower perceived staff burden than if requirements are implemented as additional work to staff. Measures collected from program initiation can also be used to assure that fidelity to treatment models is maintained over time. Ideal performance measures should have high utility and minimize collection burden.

Insights gleaned from these measures can help early intervention CSC programs establish benchmarks for comparison across programs, and may enable them to investigate cost savings. Several of the early intervention CSC programs interviewed relied on hospital and emergency room utilization data to estimate cost savings as a result of the first episode programs. If these utilization measures can be obtained from existing administrative data systems (e.g., Medicaid, hospital, etc.), high utility information can be gathered with minimal burden to program staff.

Good measures are clearly defined and operationalized. The most common definitional issues seem to arise related to the duration of untreated psychosis (e.g., when did treatment begin?), highest grade/level of school completed (e.g., does completed mean finish, pass, or graduate?), and employment (e.g., what counts as work?). Ideally, measures must have high utility while placing very little collection burden on providers. Minimizing collection burden helps ensure greater participation and enhanced data quality.

Based on ratings of utility and burden, and follow-up interviews with staff from seven early intervention CSC programs, measures of how well a consumer is meeting his/her life goals are among the most important. This includes measures in the employment, school participation, and social connectedness domains. Other domains identified as having very high importance include identification, intake, and enrollment; program involvement; psychiatric hospitalization; emergency room use; physical health; social connectedness; and prescription adherence and side effects.



A variety of standardized instruments exist to help first episode programs collect performance measure data. Many of these instruments were not specifically developed for early intervention programs. Therefore, some early intervention programs have developed their own instruments to collect these data. The highest rated standardized instruments in terms of clinical and administrative utility are the Clinical Global Impressions Schizophrenia Scale (CGI-Sch; clinical and administrative utility = 5; collection burden = 2), Clinician-Rated Dimensions of Psychosis Symptom Severity Scale (clinical and administrative utility = 5; collection burden = 3), Columbia Suicide Severity Rating Scale (clinical and administrative utility = 5; collection burden = 2.5), and the EASA Intake Form (clinical and administrative utility = 5; collection burden = 3).

When deciding which outcomes to measure, it is important to consider the context in which the program operates (e.g., public vs. private) and the amount of burden collecting the data will place on the program.

[*Note:* Click <u>here</u> to access copies of, and/or links to, several of the instruments referenced in this document.]



## Appendix A: Example of the Utility and Burden Assessment Form

## CALGARY EPTS OUTCOME MEASURES: UTILITY AND BURDEN ASSESSMENT

As part of our ongoing efforts with SAMHSA to help states effectively implement first episode programs with their Mental Health Block Grant 5% Set Aside funds, NRI and NASMHPD have been asked to develop a list of outcome measures states should consider using to assess the effectiveness of their programs. We are attempting to evaluate outcome measures for the following 15 domains:

- Identification, Intake and Enrollment
- Living Situation/Homelessness

- Program Involvement
- Improved Symptoms
- Functioning
- Suicidality
- Legal Involvement
- Employment
  - yment
- School Participation

- Psychiatric Hospitalization
- Use of Emergency Rooms
- Social Connectedness
- Substance Use
- Prescription Adherence and Side Effects
- Physical Health

Using the program profiles provided by the Calgary EPTS Program for the <u>Inventory and</u> <u>Environmental Scan of Evidence-Based Practices for Treating Persons in Early Stages</u> <u>of Serious Mental Disorders</u> ("Inventory"), we have identified 24 outcome measures and 32 fidelity measures the program uses to evaluate the effectiveness of the FEP program. Please note that we did not identify any outcome measures under the following domains:

- Functioning Use of Emergency Rooms
- Legal Involvement
   Social Connectedness
- Living Situation

Substance Use

If the Calgary EPTS Program does use outcome measures within these domains, please insert them into the table below in their appropriate domain headings, and indicate from where the data for these measures are derived (e.g., Medicaid records), or send Kristin Neylon the additional measures and tools for her to insert into the table.

Once you have reviewed the measures in this document, and provided utility/burden ratings for each, we'd like to schedule a follow-up interview to gather additional contextual information about the use of these outcome measures to make programmatic and/or clinical decisions. Please contact Kristin Neylon (<u>kneylon@nri-inc.org</u> / 703-738-8174) with any questions. **Thank you!** 

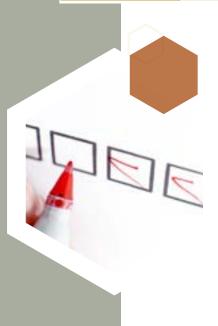
Source: Administrative Records

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain			
	If the collection burden is the same for all measures on the EASA Outcome Review Form, please indicate the collection burden here (no need to evaluate burden for all if this is the case): 1 🗆 2 🗔 3 🗔 4 🗔 5 🗔 N/A 🗔						
	Time from Referral to First Appointment	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			
Identification, Intake & Enrollment	Population Based Admission Rate	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			
	Proportion of Referrals to EPTS First Admitted to Inpatient Services	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			
	Proportion Declining Follow-up at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			
Program Involvement	Proportion Declining Follow-up at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			
	Proportion Declining Follow-up at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.			

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
	Median Duration of Untreated Psychosis	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
Improved Symptoms	Assessment of Tardive Dyskinesia	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Attempted Suicide — Percent at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
Suicidality	Attempted Suicide — Percent at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Attempted Suicide — Percent at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Work (Percentage in Competitive Employment) at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
Employment	Work (Percentage in Competitive Employment) at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Work (Percentage in Competitive Employment) at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

		Utility	Burden — How difficult are these data to collect?	Comments — Including
Domain	Outcome Measure	(Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	(Please score 1-5, 5 being most burdensome to collect)	what should be added to better assess this domain
	Education (Percentage Participating in Education) at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
School Participation	Education (Percentage Participating in Education) at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Education (Percentage Participating in Education) at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Cumulative Admissions to Hospital at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
Psychiatric Hospitalization	Cumulative Admissions to Hospital at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Cumulative Admissions to Hospital at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
Prescription Adherence and Side Effects	Acute Episode Medication within Guidelines	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Physical Heath	Weight (Percent with BMI < 25) at One Year	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Weight (Percent with BMI < 25) at Two Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Weight (Percent with BMI < 25) at Three Years	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.



Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Fidelity Scale	Timely contact with referred individual	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Patient and family involvement in assessments	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Comprehensive clinical assessment at enrollment	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Psychosocial needs assessed for care plan	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Individualized clinical treatment plan after initial assessment	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Antipsychotic medication prescription	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Fidelity Scale (cont.)	Antipsychotic dosing within recommendations	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Guided reduction in antipsychotic medication	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Clozapine for medication- resistant symptoms	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Patient psychoeducation	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Family psychoeducation	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Individual CBT, delivered by an appropriately-trained professional, for Treatment Resistant Positive Symptoms or for Residual Anxiety or Depression	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Individual and/or group interventions to prevent weight gain	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Annual formal comprehensive assessment documented in health record	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

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Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Fidelity Scale (cont.)	Assigned psychiatrist	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Assignment of case manager	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Supported employment	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Active engagement and retention	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Community living skills	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Crisis Intervention Services	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Participant/Provider Ratio	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Fidelity Scale (cont.)	Practicing Team Leader	1	Collection Burden: 1	Click here to enter text.
	Psychiatrist Role on Team	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Multi-disciplinary Team	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Duration of FEP Program	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Weekly multi-disciplinary team meetings	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Targeted public health education	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

Domain	Outcome Measure	Utility (Please score 1-5, 5 being most useful for assessing clinical and administrative performance)	Burden — How difficult are these data to collect? (Please score 1-5, 5 being most burdensome to collect)	Comments — Including what should be added to better assess this domain
Fidelity Scale (cont.)	Targeted Health/Social Service Provider Education	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Communication Between FEP and Inpatient Services	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Explicit Admission Criteria	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.
	Population Served	Clinical Utility: 1	Collection Burden: 1	Click here to enter text.

Thank you!

# Q & R

# Appendix B: Notes from Follow-Up Interviews with CSC Programs

#### **ONTRACKNY CALL NOTES**

May 7, 2015

#### **Participants:**

Lisa Dixon, M.D., OnTrackNY Ted Lutterman, NRI Kristin Neylon, NRI

The purpose of this call was to identify which outcome measures OnTrackNY has found most and least useful, and how the measures are collected so as to inform nascent first episode programs.

## Question: If a state or an organization is trying to set up a new program, which outcome measures and tools should they first consider using?

- It is critical to track institutional services, including ER use, and hospitalization. These indicators are important to policy makers because they reflect resource use as being markers of poor clinical outcomes.
- Social and family functioning, including work and school participation, and friendships. For policy-makers, things should be straightforward and intuitive. Is the person in school? Is the person working? Are they competitively employed? Do they work full or part time? How is their performance level at work? These metrics are useful for policy makers.
- Recovery is important, and is embedded in a self-report. OnTrackNY will begin
  using the CSI for consumer self-reports in the near future. Looking for measures
  that help identify a person's sense of well-being and hopefulness.
- Because shared decision making is central to the model, if clients are independently surveyed (e.g., as part of routine satisfaction surveys), you can build in questions to get at whether shared decision making is occurring (e.g., When you and your Team have talked about your treatment, how much did you feel that decisions about your treatment were joint decisions between you and your Team?)
- Dr. Dixon really supports the MIRECC GAF Scale because it integrates many indicators into one, simple number (scale 1-100).
- Once a consumer leaves the program, OnTrackNY attempts to follow-up every three, six, and 12 months.
- OnTrackNY uses some of the social functioning and well-being questions from the MHSIP to determine consumer satisfaction with services.
- Metabolic indicators are also critical, including weight and substance abuse.

- One of the most important research issues is how long consumers experience improvement, and what happens next?
- Big lesson: keep it simple and straightforward. The more people have to measure, the greater the burden and the chance for comprising accuracy.
   Whenever possible, use information already being collected for other purposes (e.g., claims data, electronic medical records).
  - When Dr. Dixon consults with potential and developing sites, she tells them if there's infrastructure to administer an instrument, and they know how to use it, then they should build on it to keep the process simple.
- OnTrackNY would welcome information from the PANSS; however, the training requirements for the PANSS are too burdensome to implement this research measure in routine practice. Instead, OnTrackNY will use the CSI and MIRECC GAF as symptom measures.

# Question: Over time, programs may have eliminated or changed measures that haven't proved useful. Have you dropped or modified any measures, and if so, why?

- OnTrackNY initially began as an NIMH RAISE site, and transitioned into OnTrackNY. Because of this, the program had to make do with fewer resources and do things a bit differently. For instance, the RAISE team started with a research team that could do independent assessments. While OnTrackNY has a training team, it is not being delivered as research and does not have staff that can do independent interviews.
- OnTrackNY started with data that came through reporting forms that each site fills out for each client at baseline, and then every three months. These data are collected through an overall program components form the team leaders have. This is where the program receives most of its data. They are currently considering slight modifications to the form. One round of modifications has already occurred, primarily to provide additional clarity because people did not always understand the questions, and they did not have appropriate responses (for instance, they needed to add a "Not Applicable" option to some of the responses).
- Because OnTrackNY believes it is insufficient to only get feedback from clinical staff, OnTrackNY is working to get feedback directly from clients. The program looked for assessments and strategies that will give the clients a voice and do not require extensive training to administer. OnTrackNY will use items from the CSI to get symptom measures that came directly from the client. They will also ask questions about process, including the consumers' experiences about shared decision-making, satisfaction with the program, and service-related recovery. The goal is for clinical teams to not be intermediaries for these metrics. The MIRECC GAF is the only instrument the program is using that requires training. They use the social and occupational functioning subscales. They are also using the symptoms subscale, but will supplement that with the CSI.

Question: Do you use different tools to measure outcomes for different age/cultural or other subpopulations?

• Not at this time. Clinicians use the same forms for all clients.

## Question: Do you use translations of tools to measure outcomes for non-English speaking populations?

 Since clinicians fill out forms, this is not relevant now. However, as we move to getting feedback directly from clients, we will have to have tools translated into the languages used by participants.

## *Question: Does your program have multiple sites? If yes, do they each use the same data collection methods/technologies, or do they all have their same approaches?*

• Each site uses the same approach and submits data to a centralized database. See above.

## Question: Do you have written performance expectations of what program teams are supposed to do?

 The program has written performance expectations (attached at the bottom of the document).

## *Question: What performance expectations have been the most difficult for program teams to meet?*

• We are just beginning to learn about this and each program is different. One program may have limited inclination to provide services in the community while another may have trouble providing 24-hour phone access to clients.



NRI identified a number of measures for OnTrackNY as it completed the *Inventory and Environmental Scan of Programs for the Early Stages of Serious Mental Illnesses.* 

#### MIRECC GAF:

- The MIRECC GAF will be used to evaluate improved symptoms, augmented by the CSI, as reported by the client.
- Have training tools and vignettes for training on the MIRECC GAF. Like the tool because it has an intuitive 0-100 scale. Use the clinician-administered version, updated at intake and every three months. Clinicians might find it burdensome because it takes time to think about.
- All programs are subsidized by the state, and this is one requirement, so the clinicians must complete it. Target is 100% response rate, regardless of how their time completing the MIRECC GAF is billed.

#### Outreach, Identification, and Engagement:

- Really interested in the timeliness of response. The tricky part of this instrument is the operationalization of expectations. For instance, what percentage of individuals need to be screened within seven days? And what percentage initiate eligibility evaluation? Numbers have not been inserted yet because they do not know what a reasonable expectation for the minimum is. The goal is to have the screening process be sufficiently engaging and not aversive so a potential client will actually complete the evaluation. OnTrack NY uses a referral flow-chart to track engagement indicators. These are updated at referral and every three months. The following indicators are really important, but a standard for success has not been established:
  - X% of individuals who were offered an evaluation completed an evaluation.
  - X% of individuals were deemed eligible to enter the program.

#### Colorado Symptom Index (CSI):

- The CSI will be used to evaluate improved symptoms.
- Improved functioning: look at work and school participation.
- Data are collected at intake and will be updated every six months.
- Still deciding if this will be automated or a paper form; may be both. Want to create it in such a way that people can complete the forms in the waiting area.

#### Suicide:

- Suicidality is a focus area. Whether a person has had suicidal thoughts or attempts is asked during programmatic updates.
- The program recommends using the CSSRS; however, if sites have their own standardized method to assess suicidality, they are welcome to use their approach.
- It is a common flag reported in the database.
- Suicidality is a low-base rate phenomenon, so it is a measure that is hard to track in a small sample.

#### Living Situation/Homelessness:

- This is asked in the programmatic assessment form.
- It is updated every three months.
- The majority of people in services live with their families. This population is different from the standard SMI population because they are usually transition-aged youth and young adults.

#### Hospitalization/Re-hospitalization/ER Use:

- These are very important measures.
- Clinician-reported. OnTrackNY does not rely on Medicaid database because most clients are not receiving Medicaid. Many have private insurance or are uninsured.
- Ask and report every three months the following:
  - Number of hospitalizations
  - Lengths of stay
  - Type of hospitalization
  - ER use
- · All part of one form.

#### Substance Abuse and Side Effects of Medication:

• These are very important indicators, and they are collected. The exact measures are included in the forms she sent NRI.



#### **EASA PROGRAM CALL NOTES**

June 9, 2015

#### **Participants:**

Tamara Sale, EASA Ted Lutterman, NRI Kristin Neylon, NRI

The purpose of this call is to discuss in further detail the utility and burden of the outcome measures used by the EASA FEP program. Feedback on the format of the evaluation form and interview protocol will also be helpful, as they may be modified for future interviews. The layout of these notes is based on the questionnaire sent to Tamara Sale prior to the phone interview.

#### 1. We have a list of 44 measures currently used by the EASA FEP program. Over time, has the program eliminated or modified any outcome measures that haven't proved useful? If so, which measures and why?

 Response: This is an ongoing process. Discussions are currently taking place as to whether we should integrate the QSANS and the QSAPS. In 2013, the program went through an extensive process to review what data were being collected. To inform the process, they looked to Don Addington's document about core measures, and conducted some literature reviews and cross-referenced what EASA collected with what the literature recommends. Based on this process and the feedback they received, some measures were eliminated and others were added. The measures that were eliminated were rarely or never used, and the accuracy of the measures was questioned. For instance, the program was asking questions about social functioning and hobbies, but ended up eliminating the measures because they were not used frequently enough. They are currently considering bringing them back in a different form. Because EASA did not start out as a research program, measures were used for quality improvement and benchmarking. Now, the program wishes they had included more clinical measures, because when it comes to writing papers and presenting posters, the level of data they would like to have is just not there. There is an agreement on a set of really core measures, followed by other measures that they would like to integrate, but integration must be done in a more systemic way. The feedback from the provider network is that they do not mind adding measures, but they want to make sure there is real clinical utility in using them. The national process of consensus is incredibly helpful to the EASA program, especially how to identify simple clinical measures that have both a research and clinical use. During their current review, clinicians, program participants, clinical supervisors, and data reps provided feedback; Tamara will send these results to NRI.

## 2. If you were starting over again, what outcome measures would you implement that you are currently not collecting?

 Response: Tamara would look for simple quality of life measures that are not too cumbersome. She would also try to include some basic clinical measures that would allow her team to document symptomology a little better. She would also include social network measures, as well as measures about metabolic disorders. EASA has talked about asking what medicine people are on, but it is difficult to integrate due to accuracy issues. To resolve this, she would try to have a separate research process where the program actually interviews consumers directly; however, this presents a resource and logistical challenge. An area where EASA is really weak is that they do not have a good direct feedback process for people experiencing care. They are working on this right now. All of the tools EASA uses are homegrown, that resulted out of the EDITH study they implemented in five counties. EASA originated in 2002 when it first created programs, and has evolved over time. Based on their interactive process with clinicians, the feedback from the clinicians is that the tools are manageable to them, and the burden in implementing them is not too great. When they have pushed to implement national tools, such as the BRFSS, the program has gotten more pushback. When implementing new tools and measures, it has been important to show how the tools and measures will be useful to the clinicians. Tamara is really interested in how the University of Maryland has integrated some of the clinical tools into the decision-making process at the clinical level.

## 3. Which measures would you most recommend to states implementing a new FEP program?

- Response:
  - iv. Hospitalization information is extremely important and helpful. It is important to include both the length of stay in the hospital, and whether the person was involuntarily committed.
  - v. School and work measures are critical measures.
  - vi. Family involvement is important.
  - vii. Insurance data has been extremely important, for sustainability discussions.
  - viii. The degree to access quantity of care has proven useful from an administrative level to understand what service delivery actually looks like.
  - ix. Referral source information is extremely helpful, as is tracking all referrals, including those who screened out. This information helps determine accuracy and impact of community education activities.



x. EASA has not tracked the duration of untreated psychosis, but they are working to include this as it is an important measure. They were not tracking because there was not agreement on what tool to use. Now, a series of interviews are conducted when someone is referred to the program that includes a retrospective review of how the symptoms have manifested and progressed over time. This helps establish psychosis risk syndrome, and may include going back to the family, referent, and young person to walk through how they got to this point. Some are willing to share everything, while others are not as willing to talk. The level of information supporting each conclusion varies depending on the person.

## 4. Have you documented cost savings to the behavioral health system resulting from the implementation of EASA?

 Response: EASA has access to the hospital data, which can be used as a proxy for cost savings. EASA has done some estimates, and has tried to do a population-level study but did not work out well due to a lack of quality data from the state. Some hospital data from the Hospital Association has shown some significant declines in hospitalizations in the original EASA site. Tamara would like to spend more resources trying to capture this trend. EASA has not tried to get ER data. They primarily rely on reports from the counselors, which is not always accurate. EASA does collect legal involvement data, which is important. The Hospital Association does have ER data at a population level, and EASA would like to have that dataset available to look at ER use and hospitalization to see if the overall program is having an impact on those, and to see if people are or are not making it into the program. ERs are a referral source that is being tracked. If being referred out of the ER, the mental health crisis people make the referral because they do the assessment at the ER. It may also be true that people come into the ER several times without a referral to EASA being made. EASA requests that programs do a pathway to care analysis - ask where they went for treatment, what type of responses they received, and to use this information in the community education activities. This information is not collected in the state database.

## 5. Are different tools used to measure outcomes for different age, cultural, or other sub-populations?

 Response: In terms of different populations, there are not different tools for separate populations. However, data may be analyzed looking at different populations. For instance, they have used that information to look at penetration rates, dropout rates, etc., but none of the forms are modified to ask questions in a different way.

## 6. Do you translate the tools to measure outcomes for non-English speaking populations?

• Response: Same as 5.

## 7. Does each EASA site use the same data collection methods/technologies, or do they all have their own approach?

 Response: Each site uses the same forms. Some providers enter their data into their own EHR and some have figured out how to integrate elements into the EHR data collection. Every provider collects the same data and submits it to the program, but everyone has a different EHR, and some sites do not even have an EHR. Concurrently, there is a parallel process at the state where they have created a centralized data system called the Measurement Outcome Tracking System that collects some of the same elements that EASA tracks. The MOTS actually reports some of the same data elements as EASA, and collects every quarter. EASA is talking with the state to see how to eliminate some of the EASA measures that are collected by the state, so EASA can just get the data from the MOTS to relieve some burden on providers. Currently, the state is relying on EASA for some administrative data, and there is some duplication of effort that is fairly problematic.

## 8. Is there a central database that collects outcome measure data for each of the program sites?

Response: EASA has a central data collection system, and a longitudinal database that goes back to when the Oregon Health Authority started funding the program. The data goes back to 2002, and EASA can access to 2008. The state is currently transitioning its data to Portland State University. A HIPAA compliance system had to be built. Data can be entered remotely through a portal, or uploaded through a data transfer. Data are uploaded every quarter. Providers indicate this frequency is just about right – any longer than that, people lose data or forget to submit. There have been some standards where someone is discharged before the quarter, so their data would be submitted within a week of discharge to ensure that data are submitted.

## 9. Do you have written performance expectations of what program teams are supposed to do?

Response: EASA has a whole fidelity tool with practice guidelines. These are
not captured in the data system. To evaluate, program administrators go on
site to EASA programs and evaluate based on a rating system that includes
performance expectations. A data manual is updated periodically.



## 10. What performance expectations have been the most difficult for your program teams to meet?

Response: This is a challenging program to manage because there are so
many different pieces. The community education effort is the hardest effort to
maintain for providers. In addition to community education and outreach, there
are data submission requirements, and all the things that go along with running a
successful program. The biggest challenges have been maintaining community
education efforts and high staff turnover. It is difficult for providers to meet
performance expectations with new people coming on board frequently. Some
programs have greater challenges at the agency level, not necessarily the EASA
level. There are certain programs where individuals hate data; therefore, EASA
is always having to handhold and cajole to get them to submit data. Providers do
not receive reimbursement incentives. Given this, providers have done really well
with performance expectations. Smaller programs tend to struggle more because
they have fewer resources available.

## 11. How do you know whether program teams are providing all of the components required of the program?

Response: This is part of the fidelity process. EASA has gone through a process
of prioritizing which components are essential, and which are okay to score lower
on. The cutoff score is 80 percent on the fidelity tool, and certain components
are required for a program to pass. When conducting the fidelity process, EASA
looks at charts, interviews clinicians, administrators, and program participants.
EASA looks at a variety of different pieces from different perspectives.

#### **EASA Outcome Review Form:**

#### 1. How are data collected through the EASA Outcome Review Form?

 Response: The clinician fills the form out directly. They ask that whoever is most familiar with the client be the one to complete the form. This is usually how it happens. Sometimes, administrative records are used in the process, and sometimes forms are filled through memory. This is obvious because the responses are not always accurate.

#### 2. It appears that data are collected at intake and once per quarter, is this correct?

• *Response:* Yes, once per quarter, at intake, and discharge. The Community Education data are collected as the outreach is conducted.

- 3. For each measure that is ranked less than three in utility, please describe the weakness, and how you would modify the measure to improve its utility:
  - Response:
    - ii. If the client had legal involvement, was it related to symptoms, substance abuse, other? This measure has not really been used; it is also somewhat subjective and would require additional data to interpret. Legal involvement/ status is actually really interesting and important; although, EASA has not used the data the way they should. The part about relationship to symptoms is difficult because they do not have enough data about what the crime was. EASA has no way of knowing what really happens, and how it may or may not have been related to symptoms. To be useful, additional information is needed.
    - iii. How many weeks did the client work in the last guarter? This measure is potentially useful, but EASA does not tend to use it much. It really requires people to track a level of detail unavailable to them. When collecting on a quarterly basis, this is especially difficult. Any time you have to start calculating the number of weeks, it is a challenge. The biggest issue is that people are doing this from memory, and are having to collect a great bit of detail. Some program sites have collected the data through voc rehab records — they collected the start date, nature of the job, income level, end date, and reason job ended. Some providers are also tracking benefits information. This is much more useful because it is more detailed and accurate. Unless providers can collect start and end dates through a systematic method, there is no confidence in the guality of the data. Some providers are tracking school information the same way. This has been really useful, but it requires a commitment on the part of the team. Tracking benefits would be really interesting, because most people do not earn benefits. EASA also asks about federal disability status, and whether they are applying for disability. They have found a high percentage of consumers have no work experience, not even volunteer. Because of this, there is little use in collecting job information.
    - iii. Is the client currently prescribed psychiatric medications? EASA does not differentiate the type of drug, so this is a fairly imprecise measure that does not tell them very much. There is a question about whether they are taking the medicine, and trying to get at adherence on their own versus other people encouraging they take their prescriptions. This is an interesting area, but it is highly subjective and its accuracy is questionable. It is interesting to cross-reference against the substance use category and hospitalization. However, the data could never be published. There has been debate over whether to eliminate this measure, but they ultimately decided not to. They also came close to asking about antipsychotics versus other medicine, but decided that was too much detail and would result in inaccurate information. The Young Adult Leadership Council developed a series of surveys for participants, and they prioritized asking about medication and informed

consent issues. This is still being actively discussed. One of the concerns of the peer group is whether or not there are any side effects associated with the medications. EASA conducted a fidelity review process with Don Addington — one of the questions about those who were medicated, how many were on higher metabolic profile medications. There is a strong correlation between how many were hospitalized, and how many were on medicines we would not want them to be on. Metabolic data are important and interesting, but it is difficult in implementation. Medical staff would have to report in an EHR or the information would have to be lifted from written notes. It is the type of measure that may be more interesting/easier to complete in a snapshot versus ongoing reporting.

- iv. Does client take prescriptions as prescribed? The accuracy of this measure is questionable.
- v. If client has a primary care physician, how many months since the client last had contact? This measure may be useful, but the program has not really used it. The administrative utility may increase if it were used more. This is a newer measure, and Tamara suspects that as the data are used the utility will increase.
- 4. Of note, the following indicators had burden scores greater than three: What types of services did the EASA team provide; How many weeks did the client work in the last quarter; Employment status; Educational milestones completed; Any overnight treatment related to symptoms?
  - Response: This varies by individual item, but Tamara is finding often that clinicians are just not tracking certain things. The number of weeks is a burden because it relies on memory. Educational status is difficult because of definitional issues. For instance, at what point has someone graduated – completed grade 12, have a high school diploma, or a GED? Grade level is surprising, but there are a number of clinicians who report inaccurately. There are similar concerns about diagnosis. These should be fairly straightforward; however, it is not uncommon for diagnoses to vary based on who is reporting. There are accuracy issues related to diagnosis, insurance, and grade level.



## 5. How are the outcome measures in this tool used to make programmatic decisions?

Response: EASA has gone through different phases. These data have been collected for a long time, and they have conducted longitudinal benchmarking to see how different measures have changed. EASA is encouraging providers to integrate EASA into local quality improvement efforts. They are in the process of developing a new set of benchmarks. They have a piece focused on community education and entry into the program, as well as retention and outcomes during treatment. There is also a piece on reason for discharge. EASA is evaluating these data at both a state and community level to compare where certain programs are with the rest of the state. Historically, the program has also used data as part of the fidelity review process. As EASA goes into a community, they create a profile, determine how many were referred/accepted/served, establish the penetration rates for different populations compared to the rest of the community, and develop comparisons to before and after how many were employed in the beginning.

#### **EASA Community Education and Outreach Form**

## 1. How are the outcome measures in this tool used to make programmatic decisions?

 Response: EASA has really learned a lot from these data. They have learned that they are not reaching a lot of people through event registrations, newspapers, and other media. This form helps create visibility about the level of effort by certain providers. There are times where providers report zero community education. With this, EASA can help get them motivated. This also helps at a state-level to talk about where to prioritize community outreach efforts. They can cross-reference where outreach is occurring versus where they are getting referrals. They have also found that schools are much less accurate than hospitals in making successful referrals: 60 percent are accepted from hospitals, whereas only 10 percent are accepted from schools.

#### **EASA Referral Form:**

#### 1. How are data collected through the EASA referral form?

 Response: Every team has an intake person, and that person completes the data for the intake form, and referral form as well. Forms are completed after direct communication with the referent. EASA expects the level of detail and accuracy will be less on these forms.

- 2. How are the outcome measures in this tool used to make programmatic decisions?
  - Response: EASA looks at where the forms originate from, and the program has the specific goal of trying to expand the number of referrals for places other than crisis beds or hospitals so as to get people into the program earlier.
- 3. Data from these forms are entered into the database at Portland State University.
- 4. Are any of the measures on this form more burdensome to collect than others?
  - Response: The referral decision is really important! It gets a lot of really good programmatic information, and whether the people referred were appropriate for care but not selected to participate (e.g., they were ill for too long, etc.). EASA has identified a sub-group of repeat referents. They have found that certain subgroups are really good at making accurate referrals. Successful referrals really come down to individual relationships. There is an administrative benefit from this information.

#### **EASA Intake Form**

- 1. For each measure that is ranked less than a three in utility, are any measures more useful than others? Are any more burdensome than others?
  - Response: The measures in this tool are used primarily for the fidelity evaluation process. This tool has been helpful, and has given a better sense of involvement of family in the beginning. There is pretty low burden with this tool.

#### **Additional Questions:**

#### 1. Are there any other measures the program gets from other data sources?

 Response: EASA has had little success getting data from the Oregon Health Authority.

#### 2. Are there other sources of data used for monitoring and evaluation?

 Response: EASA would really like to tap into additional sources, but it has been difficult enough maintaining the ongoing level of effort. EASA would like to do some targeted studies. For instance, they are really interested in doing a longitudinal study looking at the disability impact on healthcare costs. They would also like to look at some of the medication data in addition to the hospital data. A study on employment would also be interesting. EASA would also like to focus on having a follow-up interview established for people after they have left the programs, immediately and ten years after they left.

#### 3. Do CCOs have access to EASA information?

 Response: It would be nice to do something like that; however, it has been difficult to know who to connect with because the CCOs look at such a broad array, and have certain metrics for what they are focused on. EASA is in the early stage of building relationships with the CCOs, as it would be optimal to have the ability to coordinate data with them, because they collect a great deal of data EASA does not have access to. This relationship would also help to show how FEP programs reduce the costs to CCOs. A recent study showed the cost of service and utilization was significantly (one third) lower for persons who were enrolled in an early psychosis program.

#### 4. What Tamara would like to learn from other programs?

- How people use simple clinical quality of life measures within the clinical supervision process.
- EASA would like to have data that were comparable. This may involve moving toward the same tool, so that states and programs can compare their efforts to other efforts across the nation. This would help establish baselines and national benchmarks.



### EDAPT/SACEDAPT CALL NOTES

July 1, 2015 at 12:00 Easter

#### **Participants:**

Tara Niendam, Ph.D., SacEDAPT Ted Lutterman, NRI David Shern, NASMHPD Kristin Neylon, NRI

### **Discussion at Beginning of Call**

The biggest challenge to the EDAPT program is that they serve both private and public payers. The only group of people they do not serve is Kaiser-only patients. Because of the difference in payment source, EDAPT offers a completely different package of services and evaluations on the county side that are unallowable expenses through private insurance. For instance, the county pays for Supported Education and Supported Employment services, but patients with private insurance pay \$60 per hour out-of-pocket for access. The county will also reimburse for outreach and education activities, whereas private insurance will not. These types of programs are long-term investment programs that work well under a public health model. EDAPT/SacEDAPT just wrapped up their year-end evaluation. It is amazing to see people finishing school, graduating high school, and attaining employment. These are multi-generational benefits to the community-atlarge, and not necessarily a single payer. Data are necessary to show cost-effectiveness and long-term benefits.

Another challenge faced by the program is that when they enter into additional counties, there is a fear that the new program will take away existing services from existing patients. However, once the EDAPT/SacEDAPT program is established, the existing programs realize that the people being served by the new FEP program were usually already in their system of care, and were a burden to resources. The FEP program actually frees up resources to enable the existing system of care to serve they people they are equipped to serve. Education around this issue is a critical step.

One important issue related to measuring outcomes is the construction of the question. While continuous variables may be more burdensome to the clinical staff colleting the data, and may be less reliable, they often tell a more nuanced story of how the client is doing. Dimensional variables allow researchers to see change in a subtle way. While dichotomous variables (e.g., yes/no) can be meaningful, other nuances are important. With any scale, it is important to have training to determine what is considered change. For instance, if you ask, "Has social functioning improved, yes or no?" it is important to understand what that change is relative to. Also, when asking, "Do you have friends, yes or no" it is important to determine how many friends, and what the quality is of those friendships.

*Q:* It is my understanding that the Client Symptom and Functioning Reassessment Tool contains measures from the Global Functioning — Social and Role Tools, as well as measures developed by the SacEDAPT/EDAPT program. Is that correct?

*R*: This scale was developed to assess all of the outcomes that all of the programs care about across the state. Also embedded within this scale are the Clinical Global Impressions for Schizophrenia and Bipolar Disorder. Questions are also derived from the GAF-M by Hall, and the PANSS. Some of the questions are included because they are areas with high stakeholder interest (including clinicians, consumers, and families). A family advocate who has worked in an EDAPT clinic for about a year began to notice areas of importance to many consumers. For instance, the question about goals was added because of stakeholder interest. It was important to the consumers that they be asked about what is important to them, what are their goals, what do they want to work on. This is a critical consumer-driven outcome.

# *Q:* We have a list of 110 measures currently used by the SacEDAPT/EDAPT FEP program. Over time, has the program eliminated or modified any outcome measures that have not proved useful? If so, which measures and why?

R: Since 2012, the instrument has only grown, and questions have been modified. The changes dealt with the dichotomous questions, and tried to get more at the nuances of what the question was asking. For instance, at the beginning, the Role Functioning Scale asked, "Are you currently working?" The way the guestion was originally worded left out whether or not someone was volunteering; volunteering has since been added as a question. The Global Functioning Role Score that is tallied during the assessment can also be challenging to interpret. On a scale of one to ten, many fall in the range between three and five. When analyzing, it is difficult to tell what it means when someone moves from a four to a five. Questions have been added to better understand what occurs to make this change happen. One challenge with this scale that has led to these adjustments is that researchers have used it for years, and often give people credit where they should not give them credit (for instance, just because someone has the desire to get a job and is looking for a job does not mean the same thing as having a job). The questions about goals help encourage discussion between the clinician and the client, and help the clinician identify ways to better serve the client. For instance, clinicians should ask the client if they met their goals, if they revised their goals, and ultimately identify any barriers that may be standing in the client's way of achieving their goals. New guestions about income and benefits become more important once the client has stabilized. Their ability to purchase food and pay rent may be more difficult, and families may be facing eviction notices. These questions also help clinicians understand who is paying for what. Oftentimes, families carry the burden of paying for and caring for their loved ones. In addition to understanding how families and individuals are handling the financial burden associated with these illnesses, these measures also allow the program to assess costs associated with outcomes and identify who is paying for treatment (families or the state). If families are covering the costs, it leads to greater risk of family burnout. The expansion of the measures in this tool has led to an increased burden for clinicians. This scale is conducted at intake and at every six months, and takes two hours each time it is administered. Although there is an increased burden, it leads to results that are more meaningful for both clients and clinicians.

# *Q:* If you were starting over again, what outcomes would you measure that you are currently not collecting?

*R*: This question is not entirely relevant to the SacEDAPT program since the CSFRA is modified as needed to collect the information deemed relevant to the program. The CSFRA Tool was updated June 27 to include additional measures, making it the seventh version of the tool. The overall goal of these modifications is to acquire meaningful data through variables that are easily analyzed. By having both dichotomous questions, and dimensional questions, analysis can be more meaningful and thorough. For example, one can evaluate those who are working and see if they have more or less friends than those who are not working.

New measures added to the tool on June 27 include:

- Option to respond "No Goal" when asked about goals associated with current work goals.
- Prompt for clinicians to look in the Avatar Health Information Exchange for information on the client's primary care physician and dentist.
- Revision to the current living situation question. Now reads "Where have you been living this past month?" And allows the clinician to select a variety of situations, rather than just one. A space is also provided for the clinician to enter the duration of time spent in each living situation.
- Revision to legal involvement question, splitting one overall question into asking four separate, specific questions about contact with police, arrests, time in jail, and probation violations (including a spot to indicate name of probation officer; include ROI and enter into Avatar HIE).
- For ER and hospital visits, additional specifications for number of visits for medical reasons and for overdose reasons are provided.

# *Q:* Have you documented cost savings to the behavioral health system resulting from the implementation of SacEDAPT?

*R*: The population SacEDAPT works with range in age from 12 to 25 with clinical high risk of first episode psychosis, which is a very diverse population. Because of this, it is hard to figure out what is important at a standardized, "bubble-form" level. Tara is currently working on a form that can be distributed to every program across the state to analyze the effectiveness of all programs, including by cost. To do this, she is trying to determine what the "heavy-hitting," necessary questions are that are applicable across programs. Once this is done, an analysis on cost effectiveness of the SacEDAPT program can be evaluated as compared to all other programs.

*Q:* Are different tools used to measure outcomes for different age, cultural, or other sub-populations? Do you translate the tools to measure outcomes for non-English speaking populations?

*R*: No — the same version of CSFRA is used for all populations. All clients are Englishspeaking; however, parents may speak many languages. To communicate effectively with the parents, the clinician may modify the tool's language.

# *Q:* Does each SacEDAPT site use the same data collection methods/technologies, or do they all have their own approach?

R: Each site does have EHR capability; however, they use different EHR systems. There is no data-entry system. Clinicians write detailed case notes that summarize the results of the CSFRA. Results are kept in the clients' charts that can be accessed any time. The assumption is that clinicians will go back and review prior case notes to determine baseline and change. Data are entered into an Excel spreadsheet by clerical staff to inform the program. An Access database is preferred. Data are collected during the sessions with pen and paper. This tends to provide a lot more comfort to both the clinicians and the clients. Not every clinician's office is set up for appropriate computer data collection. With a pad and paper, clinicians can maintain eye contact with their client, and not appear to be distracted by a computer or an iPad. The program is currently testing a phone app that collects data for a clinician dashboard. Another strategy used in EDs is having a transcriber present so the physician can work with the patient while saying things aloud to the transcriber to enter into a database. This method has not been tried with the SacEDAPT program, and has not been used in behavioral health, as far as Tara is aware. There has not been any consideration to having clients fill out their own assessments. It is an interesting idea; however, from a data collection perspective, it is challenging because some clients are non-responsive, some cannot read, while others are in high school and doing well. Comparing their responses is not a fair assessment. Also, if clients were to complete the evaluations as a first step, clinicians would have to go back to integrate. It is likely that clinicians would take as much time integrating the responses as it does to ask the questions; a task that may not be billable. However, a case manager may be able to complete these assessments (except for the CGI) as well and at a lower rate.

# *Q:* Is there a central database that collects outcome measure data for each of the program sites?

*R:* There is not currently a database that collects outcome measures from each program site. She is working with new staff to create an Access database that will allow comparisons across sites. Unfortunately, data are only collected on clients in the county system, because private insurance will not allow clinicians to bill the full time to conduct the assessment, and only allow for reassessment once per year.

# **Q**: Do you have written performance expectations of what program teams are supposed to do?

*R*: Tara has a PowerPoint training she provides clinicians related to the CSFRA. This is done at least once per year. To ensure fidelity, case notes are reviewed to ensure that clinicians are scoring accurately. Supervision is also conducted. Tara sent NRI the PowerPoint, but asked that it not be distributed, since it has been developed for her to administer.

# *Q:* What performance expectations have been the most difficult for your program teams to meet? How do you know whether program teams are providing all of the components required of the program?

*R:* The CSFRA is time consuming, and because of this, it is difficult to get the assessment completed on time. If the assessment is done late, that is okay. SacEDAPT tracks time to completion. One issue that was identified is that clinicians were not completing the form because clients were not coming in. Because of this, they added a collateral option to enable clinicians to fill out the form without the clients present.



### **Questions about the Client Symptom and Functioning Reassessment Form:**

\*\*\*Note that many of these questions are answered in the discussion above.

*Q:* No measures were ranked less than a three in clinical or administrative utility. It seems that perhaps you have already had an extensive vetting process to achieve a high quality tool. Are there any measures/domains where you think the tool could improve? The measures for substance abuse and medication compliance were ranked "3" for moderate utility. Are these areas you would like to see improvement?

*R*: Substance abuse: This question is meant to be a quick screening question to tell the clinician if they need to go to the SCID or the CODA. It is not designed to be exhaustive; just a quick check. In terms of utility for this domain, the SCID really tells the clinician what is going on.

**Medication compliance:** These data points are only as reliable as the data that are provided. Because of memory issues, clients often have a very hard time remembering to take their medications, and some cannot even tell the clinician what medications they are on. This measure tries to get really basic information: Do you ever miss a dose? The cell phone app asks if they take their medication every single day. This is a much better measure.

## **Q**: How are the outcome measures in this tool used to make programmatic decisions?

*R*: Tara had sent a report that evaluated the program outcomes from July 2011 to March 2015. As a result of this report/evaluation, the program realized that they needed to do a better job engaging people into care. A bigger push has been made to bring people into the group.

### **Questions about the SCID:**

#### **Q:** How are data collected through the SCID?

*R*: All available data are used, including hospital records, administrative records, patient interviews, family members. Using multiple data sources is essential to verification and accuracy of data.

#### Q: How often are data collected?

*R*: Data are collected in a research lab. Case conferences are held with the entire team where they discuss changes in symptoms between baseline and six months to determine diagnosis. Sometimes if there is any doubt about diagnosis, they will re-do the assessment.

# *Q:* Of note, the burden evaluation for this tool was rated four out of five. Why is this so burdensome to collect?

*R*: Conducting this tool is time consuming. For some people it is really hard, because they do not think the way the algorithm requires. Clinicians can be really concrete in their thinking and have a hard time integrating knowledge of this instrument with flexibility. Some clinicians need extensive supervision. Although burdensome, this tool provides exceptional data and helps clinicians determine if someone has dependence. It can be so easy for clinicians to misattribute things, and the SCID makes sure they cover all their bases.

#### Q: Do you track people who refer to your system?

*R*: Yes. Outcomes are tracked to determine time between identification and intake, and barriers to untreated duration of psychosis. See outcomes report.

#### **Q**: How are the outcome measures in this tool used to make programmatic decisions?

*R*: This tool can lead to really interesting discussions about whether or not people are psychotic. Same with the SIPS. The line is tricky to determine. The SCID and the SIPS are used to determine psychosis. If someone sees shadows that are not there, they are not necessarily psychotic; whereas they might be diagnosed with psychosis in the community. This program feels really strongly that medications should not be given to children in an attenuated symptoms state. They do not want to over-medicate children who are not psychotic.

#### **Questions about the SIPS:**

#### Q: How are data collected through the SIPS?

*R*: Data from SIPS are collected at baseline and are collected through a clinician interview. The administration of this tool takes 1.5 hours to complete. The positive symptoms of the SIPS are better than the SCID in terms of getting people to actually answer about what is going on. The SCID is stigmatized, and the SIPS is meant to get people to talk. Clinicians love the SIPS because it gives them more data to make a good decision.

#### Q: How often are data collected?

#### R: Data are collected at baseline.

### Q: Of note, the burden evaluation for this tool was rated four out of five. Why is this burdensome to collect?

*R*: Clinicians must be thoroughly trained to administer this tool, and training takes a lot of time.

### Questions about the Columbia Suicidality Severity Rating Scale: *Q: How are data collected through the CSSRS?*

*R*: Responses are collected via live interview. Tara loves this tool and recommends that every program use this tool. It is used as part of the functioning reassessment.

#### Q: How often are data collected?

*R*: Data are collected every six months or when an episode is reported. The Sacramento County hospital system has an alert in its data system to call the SacEDAPT program any time one of its patients is admitted to the hospital.

# **Q**: How are the outcome measures in this tool used to make programmatic decisions?

*R*: The measures in this tool are used to determine 5150 involuntary commitment holds for patients. Clinicians love this instrument. It takes time, but it requires the clinician to be thorough and keeps patients safe. It evaluates actual intent versus a person's wish to die. So many people are diagnosed with passive suicidal ideation, and this helps people understand the difference, ultimately preventing unnecessary hospitalization.

# Questions about the Sacramento County Co-Occurring Disorder Assessment (CODA):

\*\*\*Note: Tara would need to get permission from Sacramento County before authorizing the sharing of the instrument.

#### Q: Is this a standardized assessment scale?

R: This tool is used by Sacramento County; no other sites use this tool.

#### Q: How are data collected?

*R*: Data are collected via live interview at 12 months and 24 months. This is not administered regularly as part of a functioning measure. It is a requirement.

#### Wrap-Up Discussion:

#### Q: What would be helpful for you as we move forward?

*R*: Tara is excited to read this report to see how other programs approach outcomes, and where they succeed. This was part of her motivation in participating. She appreciates SAMHSA's investment in trying to come up with something that works and can work well. This has to be understood and vetted at a national level when talking to payers. She would like to understand what some of the barriers are to assessment, so she can better understand why some programs do not track certain measures. It is a challenge for some people to embrace the usefulness of data, and that the associated burden is worth the data collection.

She would also like to know what the makeup of the other programs' clinics is. In her experience, masters-level clinicians have not been trained to ask basic questions; whereas Ph.D. level clinicians have.

# *Q:* Tamara Sale from the EASA program is interested in knowing how other programs collected data on the duration of untreated psychosis. How are you getting this information?

**R**: SacEDAPT collects this information through the SCID. It assumes that questions are asked about onset of symptoms. Each one of her clinicians are SIPS and SCID trained, and every one identifies the onset of prodrome and the onset of psychosis. They are able to identify the month and year of symptom onset.

It was noted that this is the first program NRI/NASMHPD had spoken to that uses the SCID. Tara recognized that this is a decision point around whether to collect quality data, or collect data that are feasible. These two ideas are often in conflict. The SacEDAPT program tends to err on the side of quality. While they always try to manage feasibility, they will not allow someone to do a simple interview to determine psychosis. These diagnoses carry a significant stigma burden for the individuals and their families. There are also treatment implications associated with medications that tend to have significant side effects.

### *Q:* A lot of states are discussing transitioning from DSM-IV to DSM-V or ICD-10. What are SacEDAPT's plans?

**R**: For now, the program is sticking with DSM-IV. Their primary concern is knowing whether someone has psychosis or not. When it comes to treatment, decisions are made based on symptoms, not on diagnosis.

#### Additional Comments:

Tara recommends we reach out to Hope Graven at the REACH Program in San Diego County. While universities are leading most FEP programs, a private company that provides services through contracts is leading the REACH Program. This is a different business model that may have a different approach to monitoring outcomes. It is very important to acknowledge that business are entering into this field to make money.

### **OHIO BEST CENTER'S FEP (FIRST) PROGRAM CALL NOTES**

July 17, 2015

### **Participants:**

Vicki Montesano, Ph.D., Ohio BeST Center Chris Buzzelli, Ohio BeST Center Ted Lutterman, NRI Mihran Kazandjian, NRI Kristin Neylon, NRI

### Review of the Ohio BeST Center's FEP (FIRST) Program:

The BeST Center works with community mental health agencies to implement evidencebased and best practices. BeST Center staff provide a comprehensive training package with ongoing follow-along supports. Included in this package are expert consultants and trainers in first episode psychosis (FIRST), Cognitive Behavioral Therapy for Psychotic Symptoms, and Family Psychoeducation. In addition, a dissemination coordinator with expertise in training and outreach and a research coordinator with expertise in data management and analysis work closely with the FIRST teams.

Currently (as of November 2015), the BeST Center is working with nine FIRST programs throughout the State of Ohio and will be training a new FIRST team in January 2016. The initial FIRST program began accepting clients in January 2010.

# *Q:* Over time, has the program eliminated or modified any outcome measures that haven't proven useful? If so, which measures and why?

*R*: The goal was to create a tool that does not place an overwhelming burden on clinicians (employed at community mental health agencies) to complete. Initially, the program tried to train the clinicians to administer the PANSS, but received pushback from the clinicians because it was too burdensome to implement. While information gleaned from this instrument can be useful, it is only useful when data are timely and complete. To get the necessary information, the BeST Center developed the BeST Practices Outcome Review Form and incorporated the Clinician-Rated Dimensions of Psychosis Symptoms Severity Scale (American Psychiatric Association, 2013).

The BeST Practices Outcome Review Form gathers a variety of outcomes (e.g., employment, education) that are collected at baseline and every six months. Data are collected by clinicians and inputted into a unique computer program developed by a partner community mental health agency. The data are readily available to all team members and are easily exported into Microsoft Excel. The goal of the outcome computer program's feature to export to Excel serves vital interests: first, with some training from BeST Center staff, team leaders at each site can generate representations of their data (tables, graphs, and charts) to be used as a quality improvement tool. Secondly, these data could also be shared with the BeST Center as a metric to evaluate and monitor the Best Center's FIRST program.

# *Q:* If you were starting over again, what outcomes would you measure that you're not currently collecting?

*R:* The BeST Center's team reviewed these measures very closely. In the real world, they would leave it as it is. However, in a perfect world, they would expect everyone to use the PANSS for clinical utility or the SCID.

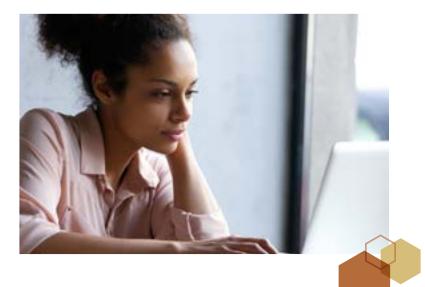
# *Q: Which measures would you most recommend to states implementing a new FEP Program?*

*R:* The Ohio BeST Center team recommends measures related to employment, education, and family relationships. Medication compliance is also important. While not a perfect measure, it is an important metric to document.

# *Q:* Have you documented cost savings to the behavioral health system resulting from the implementation of the Ohio BeST Center's FEP (FIRST) Program?

*R*: The BeST Center reviewed service utilization data for clients who had been enrolled in their first episode psychosis (FIRST) program for 12 months. Because only 24 clients had been enrolled for 12 full months, the sample was too small for accurate statistical analysis. However, the BeST Center was able to determine that the cost to enroll a client in the FIRST program was approximately \$790 per month, primarily using Ohio Medicaid mental health outpatient service rates. These estimates reflect average service use per member, per month for FIRST. By comparison, it costs approximately \$550 to \$650 per day to stay in a state inpatient psychiatric facility.

Emergency Department and psychiatric hospitalization data for clients enrolled in the program were collected through the BeST Practices Outcome Review Form and indicated very low levels of psychiatric hospitalization use.



*Q:* Are different tools used to measure outcomes for different age, cultural or other sub-populations? For instance, is the BeST Practices Outcome Review Form modified for youth? Is the tool available in any other languages?

R: The form is written at a ninth-grade reading level and is only available in English.

# *Q:* Does each BeST Center FEP (FIRST) program site use the same data collection methods/technologies, or do they all have their own approach?

*R*: For outcome measures, there is a standardized approach, and eight of the nine FIRST programs use the unique computer program developed by a partner community mental health agency to collect and extract data. One program utilizes their own data collection method for outcomes.

In addition, the BeST Center collects and maintains monthly data from participating FIRST sites by exchanging two standardized files: a master spreadsheet (MS) and service utilization data in anonymized form. The MS is an encrypted Excel file that contains a breadth of information that can be broken down into information on current or past participation in the program and referrals to the program. This document quickly allows the BeST Center to monitor enrollment numbers, duration in the program, duration from referral to intake (and admission), discharges, reason for discharge, general information, and reasons that referred clients choose not to engage in the program, and information about referral sources.

The service utilization component tracks the frequency and duration of services (e.g., case management, psychiatry, counseling, etc.) used by each anonymized client. The goals of this data at the level of the site (or team) are quality improvement monitoring due to its easy conversion into graphs and charts by month, quarter, or year(s). These data also inform about changes or patterns in the frequency and amount of services for FEP clients during tenure in the program. Additionally, receiving service utilization data from participating sites allows the BeST Center to examine information about the distribution of services.

#### Q: How often are outcomes data submitted by providers?

*R*: Data are submitted at baseline and every six months.

# *Q:* Do you have written performance expectations of what program teams are supposed to do?

*R:* The goal of the Ohio BeST Center is to implement a program that is sustainable to the agency, and can be integrated into what the agency is already doing to meet consumer needs. To ensure adherence to the model, consultant trainers are used to train clinicians on how to integrate the program into their sites. These consultations may be provided face-to-face or via video conference. The BeST Center consultant trainers are in frequent contact with FIRST teams and team leaders weekly or bi-weekly to provide consultation.

A Policy and Procedure Manual was developed to help providers understand performance expectations. Treatment manuals were developed based on the NAVIGATE ETP manuals. The expectation is that every client goes through the first five modules in the manual, and their success is reviewed and monitored at every team meeting.

Guidance on outreach was also developed, as outreach is crucial to engaging with community partners. Treatment teams are responsible for doing outreach in the community. Contacts are gathered through outreach events, and the BeST Center collects this information in order to send out monthly email updates and quarterly newsletters related to the program. Referral data are reviewed on a quarterly basis to assess outreach effectiveness, to prompt thank you letters to referral sources, and to identify trends in enrollments, including inappropriate referral trends, which are then addressed with additional education.

# *Q: What performance expectations have been most difficult for your program teams to meet?*

*R*: Outcomes! Technology has been very difficult. The BeST Center is trying to eliminate paper forms altogether. The ideal is to have clinicians complete the evaluation forms electronically while in session with the consumer so that trends can be displayed and presented to the consumer in real time, during a session.

# *Q:* How do you know whether program teams are providing all of the components required of the program?

**R**: The BeST Center staff maintains weekly or bi-weekly contact with provider sites. BeST Center consultant and trainers regularly attend FIRST treatment team meetings. In addition, team leaders engage in a monthly learning collaborative with the BeST Center consultant and trainers.

### **Questions about the BeST Practices Outcome Review Form:**

# *Q:* How are data collected through the BeST Practices Outcome Review Form? Are any parts of the form completed through administrative records?

*R*: For now, the forms are completed at the computer with the client. However, the clinicians really do know the clients well enough to answer most questions without a review. Results are discussed in team meetings.

### Q: How often are data collected?

**R**: Baseline and every six months.

#### Discussion of Measures ranking less than or equal to "3" in utility:

- The administrative utility rankings for many of the legal involvement measures was rated a "1," while clinical utility was rated a "4." The importance of legal involvement is very much a priority. It is clinically useful to know if a crime was committed because of symptoms. As far as administrative utility, these measures do not have the same level of usefulness as employment, education, living situation, and how well clients get along with family. Legal involvement has thus far not been prevalent with current clients. The BeST Center staff has recently begun working more closely with court systems, particularly with mental health courts, to introduce FIRST as a potential referral source.
- Type of substances used had moderate clinical utility (3) and low administrative utility (1). Clinically it is important to know what substances consumers are using, especially if usage habits have increased. These data are not reported administratively.
- Use of tobacco products had moderate clinical and administrative utility (3). This is included as an effort to promote integrated care.
- Medical services received since last review had moderate clinical utility (3) and low administrative utility (1). This measure reminds FIRST providers that integrated care is an integral part of wellness. If clients do not have a primary physician, team members are expected to assist clients in finding a provider.

# Questions about the Clinician-Rated Dimensions of Psychosis Symptoms Severity Scale:

**Q: How are data collected through the Clinician-Rated Dimensions of Psychosis Symptoms Severity Scale?** 

**R**: It is completed by the psychiatric provider and inputted into a computer program.

#### Q: How often are data collected?

R: At baseline and every six months.

# *Q:* This tool seems exceptionally useful with all measures rated a "5" in clinical and administrative utility. Can you explain why it is so valuable?

*R*: This instrument looks at the dimensions of psychosis. The tool only takes a couple of minutes to complete, with some providers completing it after meeting with the consumer. It allows providers to adjust changes to treatment if symptoms have not improved since the last assessment. The goal is to initiate conversations about hallucinations and delusions.

### **Other Questions:**

*Q:* There do not appear to be any specific tools or measures to monitor Improved Functioning or Suicidality. Do you have access to administrative records for these data?

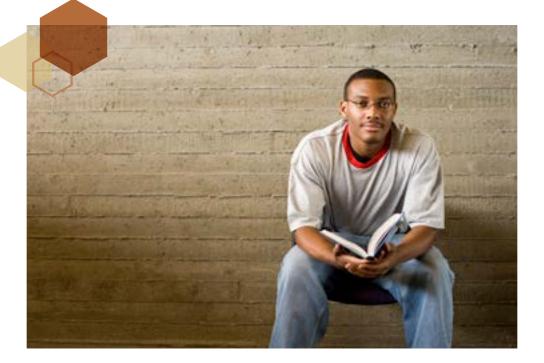
*R:* Within the manuals, there are modules on depression, anxiety, and suicidality. If clinically indicated, the clinician completes the Calgary Depression Scale for Schizophrenia. The programs are not completing a formal quality of life assessment, but are considering implementing a tool to capture this information.

# *Q:* The Ohio BeST Center's FEP (FIRST) Program is the only FEP program to ask about Advance Directives. Could you elaborate on the value of these measures?

*R*: The BeST Practices Outcome Form asks consumers about their desire to complete an Advanced Directive. This is included because several sites required it for accreditation by The Joint Commission. Regardless of accreditation, the Directive is available to any client enrolled in a FIRST program because an Advance Directive is an important component in recovery and empowerment.

### Q: What would you need to implement the PANSS?

*R*: Program staff are not sure this could be done in a community mental health setting. Even if clinicians could be reimbursed for their time, they state that the measure is overwhelming.



### **CALGARY EPTS CALL NOTES**

July 30, 2015

#### **Participants:**

Don Addington, M.D., Calgary EPTS Ted Lutterman, NRI Mihran Kazandjian, NRI Kristin Neylon, NRI

### **Review of the Calgary EPTS Program:**

Dr. Addington has been involved with performance measurement of first episode programs for the past 15 years. In 2005, he advised the network of first episode programs in the Province of Ontario, Canada on performance measures. Unfortunately, they chose not to implement performance measures when they started their programs and are now struggling to confirm the fidelity and efficacy of their programs. However, there are still efforts going on in Ontario around this issue, and a conference was held in August 2015. It is tremendous that this work is being done early in the States.

The Calgary EPTS program was initiated as a result of a competitive grant program 20 years ago. A small amount of money was awarded to demonstrate feasibility of an FEP program. At the time, Dr. Addington was a clinical researcher. He put in place a framework of individual patient clinical outcome measures; all of which were already in research use as a primary way of assessing the program. Out of these, preliminary information was collected that demonstrated the program was operating as promised. The grant ramped up for six years to provide a whole population service to approximately 750,000 people. His group then measured outcomes in that program over the next five years. Relapses were measured as the primary outcome. When this trial program ended ten years ago, it rolled over into the routine budget of the health system; for last 10 years, it has been part of the routine health system.

After doing clinical outcomes for a number of years, Dr. Addington became more interested in trying to measure performance measures that were not reliant on detailed clinical assessments. The programs still uses a number of structured clinical assessments. The research, however, has focused on the development of key performance measures.



# Questions About Performance Measures Used by the Calgary EPTS Program:

- 1. We have a list of 63 measures currently used by the Calgary EPTS program. Over time, has the program eliminated or modified any outcome measures that have not proved useful? If so, which measures, and why? The Calgary EPTS Program has narrowed the performance measures into two kinds of performance measures: one is the process measure covered by the fidelity scale which are primarily process oriented (ideally, fidelity scales measure process outcomes). The second is a list of evidence-based performance measures that were identified through the literature. These measures covering early intervention, clinical outcomes, and safety. To be in line with Health Canada, the Calgary EPTS program also measures outcomes under a variety of domains, including cost effectiveness, safety, and acceptability. Through these multiple channels, many performance measures are in place; however, in practical reality those complex frameworks do not get used in the real world. Therefore, the Calgary EPTS program has narrowed the list of measures down to include metrics that are concrete and relatively straightforward to measure. Although the program does not measure everything, and there are many domains the program does not cover, the measures used by Calgary EPTS provide a good overview of the program's functioning. One critical measure is the time from referral to first appointment. Another important measure is the number of persons still in the program at one year, two years, and three years, since one issue with all of these FEP programs is dropouts.
  - We have not identified any measures under "Improved Symptoms." Does the program monitor improved symptoms? If so, how? We do, yes. We use very standardized measures. Calgary EPTS uses the PANSS, the Calgary Depression Scale, and the AIMS. We use the addiction (Dr. Drake's Addiction Measure — Case Managers Addiction Scale). Heinrichs Carpenter Scale. These are administered at intake, annually.
  - During NRI's interviews, one common issue many FEP programs have faced is the cost of having clinicians administer these measures. How does it work in Canada so that the programs can afford to do them? Psychiatrists bill by time, and some claims relate to specific assessments of the mental state, so if they do structured assessment, they can bill the time it takes them. Not everyone agrees that these are useful to administer. The Calgary EPTS program provides education and reliability training for any new psychiatrist who joins the program. Some measures are administered by the clinicians in the program, such as the quality of life scale and the case manager's addiction severity scale.
- 2. If you were starting over again, what outcomes would you measure that you are currently not collecting? Cigarette smoking. Probably a blind spot from a long time ago. This measure is not captured in anything formal, but it is something that individual clinicians pay attention to. It is a very important measure because cigarette smoking is the largest risk factor for long-term death. It is a preventable risk factor.

- 3. Which measures would you most recommend to states implementing a new FEP program? Canada operates a public health system where everyone is insured through province-funded insurance system. Everyone has insurance, but it only covers hospital and physician services. This means that there are major challenges in funding and delivering complex team-based community programs, such as first episode psychosis services. Dr. Addington was not quite sure how the Canadian mandate to serve the whole population translates into state mental health services in the U.S. Whether it is meaningful to say that programs in the U.S. should strive to see a specific portion of the population is unknown. This depends on how the program is structured. For example, the RAISE program needed to recruit a certain number of people at each center to reach certain enrollment benchmarks for research purposes. In the RAISE study, the duration of untreated psychosis was pretty long. UK evidence suggests there is a link between a population's access to evidence-based first episode psychosis services and Duration of Untreated Psychosis. The original mandate for many of the U.S. programs has been a research-driven agenda, where services are set up because people are coming through research-driven protocols. Clinical and research funding work together; therefore, there is usually no responsibility to whole population. During NRI's interviews with program developers, differences have been noticed between programs with university funding, and those that receive funds through the community. For instance, when talking with program developers at UC Davis, they are able to use a very intensive assessment because it is university-based and they have the resources to do it, whereas county-based programs often cannot do it because it is expensive. The community programs often have to rely on state funds, MHBG funds, and now with ACA are seeing young adults up to age 26 covered, so all of a sudden they have private insurance that may pay for some of these services/screenings not covered before. Once you have an identified enrolled client, you can bill, but outreach cannot be billed. Dr. Addington noted that the duration of untreated psychosis may be important at the state level, but not necessarily at the clinical level since it is most effective as a population-based measure. The duration of untreated psychosis is related to availability and access to services; therefore, if you want to reduce DUP, you need to pay attention to the local annual incidence of new cases of psychosis and the proportion of new cases that access care. Many stakeholders in public health are seeing the duration of untreated psychosis as important. Longer the duration, the more the disability will strike and worsen outcomes. Simple and practical measures to evaluate access to early intervention services are: time to referral; median duration of untreated psychosis; population-based admission rate; and percentage admitted to inpatient prior to receiving first episode psychosis treatment services.
  - How does Calgary EPTS measure Duration of Untreated Psychosis? We
    ask psychiatrists to rate this based on all sources of information. For research
    projects, they have used a couple different measures. First, we used a German
    Measure called IRAOS that is rather detailed and time consuming. More
    recently, we switched to research to using the Symptom Onset in Schizophrenia
    (SOS) inventory, developed by Dr. Perkins from North Carolina. We think that a
    clinician's best estimate is a reasonable way of doing it in clinical practice.

- 4. Have you documented cost savings to the behavioral health system resulting from the implementation of this program? Only indirectly. For example, the goal of the first major research project was that we would reduce the relapse rate by 50%. We had the general literature at the time show there was a 60% two-year relapse, reduced to 30%. We argued that relapse prevention would result in cost savings.
- 5. How have the outcome measures in this tool/data source been used to make programmatic decisions? Outcome measures are not routinely used to make programmatic decisions. Research projects have guided the development of the program over time. Despite their availability, these measures have no impact on programmatic decisions. A knowledge translation grant was obtained to allow the research database to become a health system support database that allowed for both individual patient monitoring and program performance monitoring with key performance measures.
- 6. Do you translate the tools to measure outcomes for non-English speaking populations (e.g., French)? The Calgary Depression Scale is available in 36 languages.
- 7. Do you have written performance expectations of what program teams are supposed to do? No, there are no provincial standards that are set from outside the program; the program has developed its own research-based standards.
- 8. What performance expectations have been the most difficult for your program teams to meet? For us, it has been achieving population-based coverage. That is a local issue. In Calgary, we have gone from serving a population 750,000 to 1.5 million over the 20 years the program has been in place. Now that the program is funded from local mental health services budgets, it has not scaled up the services to meet that population's needs.



- 9. You noted in your responses that there should be a clear definition for suicide attempt, such as from the Columbia Suicide Severity Rating Scale. Do you use any of these instruments in your program? Are there any that you recommend over others? In Canada, ER visits for attempted suicide are measured and reported nationally, so these are used for rates of attempted suicide in routine mental health services. We have used structured self-report measures, such as the Columbia Suicide Severity Rating Scale in research projects. In the U.S., suicide data are collected through vital statistics. The CDC has data on hospitalization for attempted suicide and numbers of completed suicides, but general belief that numbers are underreported due to stigma.
  - Many of the programs NRI has been talking to recommend the Columbia scale. Is it cost, or is it because of the availability of data that Calgary does not use that scale? Calgary does not use the scale because it is not routinely used in mental health services. We use measures that are either driven by a research protocol or measures that are required for routine mental health services monitoring.
- 10. You note that legal involvement information is regularly collected through the health form. How is this form administered? What is the burden for administering this form? Do you have a copy you could share with us? This information is derived from the health record as recorded by the responsible clinician/case manager. The information is not collected through a routine form. It is one question on a routine intake form. The clinician asks, "Any legal involvement in the past year?"
- 11. Regarding the employment measures, you noted that a clear definition is needed for work and timeframe. How does the Calgary EPTS program define this measure? In Calgary, the program uses a definition of any current work or education. The definition of any paid work, regardless of quantity. This has to be at the time of a routine assessment at intake or annually. For example, if a patient had a job two months ago, but not on the date of the assessment, this does not count as employment. There is an equivalent definition for education. If they are in any education at the time of assessment, they are in formal education. Unlike work, if a patient is in school but currently on vacation, they are considered enrolled. NRI noted that one issue nationwide is that about 18 percent of adults in the public mental health system are competitively employed. The fear is that among 8 to 9 percent of persons with substance abuse issues are earning wages that are adequate to cover living expenses. Dr. Addington noted that in Canada, each province has a long-term disability program. Alberta recipients can work up to a specific level of income before they start to lose disability. This can be up to two days per week on minimum wages.

- 12. Living situation is tracked via admission/discharge records. Do you monitor living situation throughout a person's involvement in the program, or only at admission and discharge? If you do monitor throughout the program, how is this information captured? How frequently? The living situation is measured at admission, annually, and then at discharge.
- 13. How do you collect information about patient and family involvement? How often is this information collected? We have a staff activity reporting system, but it does not seem to work reliably.
- 14. I noticed a difference in the administrative utility ratings between these two measures: Percent of patients who have assigned psychiatrist, and Percent of patients who have assigned case manager. The administrative utility for the case manager was higher (5) than the administrative utility for the psychiatrist (3). Why is this? This is hard to understand. It may reflect different health systems. In Canada, the psychiatrist is paid from a physician's fee for service budget that is not part of the mental health services' budget.

### **Questions from Other Developers:**

What other questions would you like us to ask other program developers? What information would you like to see come out of this process? I think all the questions have been very comprehensive, so nothing really anything comes to mind. Would be very happy/impressed if we managed to encourage a very simple framework of process and outcome evaluation to happen at a national level. Or even just a number of states to commit! Would be terrific.

*Many states are discussing transitioning from DSM-V to DSM-V or ICD-10. What are Calgary's EPTS Program's plans?* We have moved to DSM-V at the provincial level. At the federal level, the required reporting system is ICD.

#### Other questions raised by your peers are:

- How do you use simple quality of life measures within the clinical
  - *supervision process?* Heinrich's Quality of Life Scale. In Ontario, they use a standardized needs assessment scale, the Ontario Common Assessment of Need (OCAN). That is routinely given and recorded on all patients. Clinicians have to be trained to administer the measure and patients are supposed to sign off on the assessment. The OCAN is used across all mental health services and is available online.

### **PREP/BEAM CALL NOTES**

August 25, 2015

#### **Participants:**

Rachel Loewy, PREP/BEAM Julia Godzikovskaya, PREP/BEAM David Shern, NASHMPD Ted Lutterman, NRI Kristin Neylon, NRI Mihran Kazandjian, NRI

1. We have identified 16 instruments (SCID, SIPS, Working Alliance Inventory, QSANS, QSAPS, PHQ-9, GAD-7, PANSS Item G-12, ASRM, GFS-Role, GFS-Social, ANSA, InterSePT Scale for Suicidal Thinking, El Suicide Risk Factor Checklist, ASSIST, and MARS), and three additional outcome measures (psychiatric hospitalization, use of ERs, and physical health) collected through medical records and self- and family-reports currently used by the PREP and BEAM programs. Over time, have the programs eliminated or modified any tools or outcome measures that have proven not to be useful? If so, which tools/ measures, and why? Overall, the program started out too ambitious in the amount and type of measures it decided to initially collect. In addition to which measures a program collects, it is important to also consider how the measures will be used, when they are used, and how often they are used. Collecting measures less frequently has been the biggest change. Initially, the program collected data quarterly, but has recently abandoned this level of frequency. Some measures are now collected every six months. The SCID and the SIPS are limited to collection at admission, and annually (at one year and at two years; assuming individuals reach this level of the program). The State of California does not require the SCID for admission; the university has decided to implement the SCID as an experiment to see how clinicians handle the structuredinterview approach, and if the costs are worth the benefits. The program anticipated that many clinicians would resist the structure associated with many of the measures, but they have found that the clinicians actually like these measures because they provide structure. Programs with a strong history in research typically include the SCID. While it is important to have research-quality diagnosis information, the SCID provides a helpful structure for clinicians to follow when talking about a diagnosis-specific program. Other programs that do not implement the SCID have been known to accept anyone living within their jurisdiction; however, when programmatic eligibility requires a specific diagnosis of a psychotic disorder, inappropriate enrollment may occur. The PREP/BEAM program has an advantage in that it is able to bill for the time clinicians use to administer these structured interviews (as part of the whole intake process). California uses Prop funds to support non-procedure services, which makes it easier to implement complex diagnostic instruments. To increase participation, especially among younger patients, these screenings are not completed in one sitting; they are rather spread out over several different meetings. Currently, there are five different PREP clinics that serve slightly different populations. Some of the lower SES individuals have

co-occurring issues, and it may take even more time to complete these evaluations. One benefit of administering these instruments is that it helps clinicians develop a relationship with the clients and build rapport. The burden is also high on the data side, as the SCID can take several months to complete; this can be reduced by training people in administering the assessments.

Initial engagement also tends to be very difficult with this population. PREP/BEAM tried several approaches to improve engagement at intake and assessment. They found that having someone other than the treatment provider administering the instruments did not work because trust was built up with the assessor, and then the person was passed off to the clinician. Therefore, it is critical to have continuity in service providers for continued engagement. They also try to offer services off-site to engage individuals in treatment where they live. Programs should consider the importance of the funding mechanisms, engagement processes, and that people with different educational backgrounds are often relied on to assess an acute diagnosis.

The PREP/BEAM program supports the use of a standard set of measures, primarily for research purposes. This information can be used to determine the needs and specific approaches that work best for certain communities. Thus far, PREP/BEAM has been successful at having all of its providers implement the SCID.

Based on a group of discussions, the program has considered eliminating the PHQ-9, GAD-7, and the PANSS Question G-12. The PHQ-9 is not clinically useful; however, the people to whom they report are still interested in understanding the results. They are considering dropping the Anxiety measure; it is sometimes used in reporting, but the frequency of data collection (every six months) makes the measure less useful. The PANSS individual items are also being considered for elimination. The program has dropped the Global Functioning – Role and Social measures, as outcomes on employment and education are much better indicators for how well an individual is functioning in the community. The MARS instrument can likely be replaced because it does not work very well for the purposes of the PREP/BEAM programs. The Working Alliance Inventory is also not critical for understanding programmatic outcomes.

It could be used to gauge the success of engagement activities, but this would depend a lot on the specific outcomes the program targets. The WAI was developed for individual psychotherapy, and this program uses a team-based approach. Because of this distinction, there are likely better ways to assess engagement. For instance, engagement can be measured by whether individuals show up and are accounted for in record keeping.

The program uses the QSANS/QSAPS for assessing outcomes related to positive and negative symptoms. While there is not a lot of data validity behind the instruments, they are easier to implement. They each have five items, ranked from 0 to 100, and are easier to teach clinicians than the PANSS. There has to be motivation for the clinicians to use the instruments. Regardless, symptoms may not be the best outcomes to measure (negative symptoms tend to be stable, and positive symptoms wax and wane, so they may not provide much reliable information). Other outcomes are likely more important: cost reduction, reduced emergency and inpatient use, functioning, etc.

Clinicians only collect measures around suicidality when clinically indicated (a client presents with suicidal ideation or intent). These measures are extremely useful clinically, but are not great measures at determining programmatic performance.

The county requires clinicians to administer the ANSA, but there has been some debate about its use. Although the ANSA is required, the PREP/BEAM program relies more on data from the employment and school specialists to capture data around goals and outcomes for employment and education. In addition to reliability for outcome evaluations, there are some issues for determining which age groups are appropriate for the ANSA. Some providers use the ANSA for clients as young as 12, while others use it for clients 16 and older. There is also a child version of the ANSA. Determining which age group is most appropriate for the instrument is one of the biggest challenges. However, if programs adhere to serving individuals age 16-25, then adult measures can be used, and the instrument will capture most individuals with first episode. Programs focusing on high risk/prodromal clients will need to shift their age groups a bit younger.

An issue with data collection in general is ensuring that providers administering the instrument understand the definitions the same way. For instance, measuring days of hospitalization, employment, and school participation needs to be defined and understood the same way across settings to allow for reliable analysis.

Goals are also important to consider to ensure that the clients are attaining success in the areas of life that are important to them. Understanding goals also helps clinicians better develop person-centered treatment planning.

The source of information is also important. Because people are at different stages in treatment, specialists are more reliable for giving information in real time. Data about hospitalization, emergency room use, and other services (before and during the program) should be collected from medical record databases; relying on patient and family self-report "is a disaster." The strategy the program uses is to take what clients report at intake, and cross reference their responses with data from facilities in the county. In certain counties, the program has been able to capture up to 80% of client records, but in some counties they are only able to capture 50% of client records. For those clients whose data are not available through medical records, research assistants work with clinicians to get the data, and refer to discharge paperwork. For certain clients, especially transition-aged adults between insurance plans, it is a long, drawn-out process. Self-report is not a reliable option of data collection.

PREP/BEAM has its own EHR that it programs to collect data from hospitals and clinicians. The program has developed research protocols for each site in every county for data collection. There is a lot of administrative burden related to data collection, and there is high turnover among research assistants. Developing relationships with providers is crucial to success.

- 2. If you were starting over again, what outcomes would you measure that you are not currently collecting? It is doubtful that the program will add any further measures; however, they are considering adding a subjective well-being measure to determine if consumers feel that their lives have improved as a result of treatment. Additionally, they are considering adding a quality of life measure to better understand if clients are attaining the quality of life they desire. An example of this would be asking about goals: e.g., if someone is working part-time that is great, but if that person would rather be working full time, or enrolled in school, that is also helpful to know.
- 3. Which measures would you most recommend to states implementing a new FEP program? PREP/BEAM recommends measures around employment, education, functioning, and service use. These measures will help programs conduct cost/benefit analyses. They are not using social functioning measures, as they have not yet found an efficient measure to capture this information. It is critical that programs ask about goals, as noted above
- 4. Have you documented cost savings to the behavioral health system resulting from the implementation of PREP and BEAM? They have tried, but have ultimately decided to leave this process up to health economists. Because of the special funding stream that supports the program, they do not have to demonstrate cost savings. However, they do report how many prior-year clients were served, and show reductions in hospitalization, and what may happen if the clients were not enrolled in the program. They have an idea of how it could be done, but have not successfully completed a cost/benefit analysis. The biggest challenge is that the clients served by PREP/BEAM are not chronic patients, so they cannot answer the question of what their average hospitalization costs for two years would be. There is a nice paper from Yale that looks at treatment as usual and shows a drop in hospitalization, because it will happen with chronic patients. When PREP/BEAM decides to do a write up, they will compare their program to treatment as usual to show an approximation of cost savings. It is not formal research, but it is a start.
- 5. Are different tools used to measure outcomes for different age, cultural, or other sub-populations, including language? ANSA has a children's component, but all other instruments focus on adults. There may be some tools translated into Spanish and Cantonese, including the multi-family group evaluation and family satisfaction surveys.
- 6. Does each PREP and BEAM site use the same data collection technologies and methods, or do they all have their own approach? They all use an EHR. One county developed its EHR separately, while the other four counties use the same EHR. There are some county-specific measures related to intake that are adapted to the EHR systems used by the providers.

# 7. Is there a central database that collects outcome measure data for each of the five program sites?

a. If yes, how often are these data collected and submitted to the central database? Yes, there is a central database at the PREP/BEAM offices that collects information from the five program sites. Data are collected by the program on paper through research assistants that bring responses back to the center and enter the data into the database. Research assistants track clinicians (and remind them when data are due), and then they enter and validate the data. They also administer self-report measures to clients and family members, because clinicians often do not have the time.

**b.** What performance expectations have been most difficult for your program teams to meet? Meeting performance expectations has not been a challenge for providers, even meeting expectations around outreach. However, staff turnover has been an issue. The program spends resources to extensively train staff to get to competency, and then they leave. There are too many people who are new and in training who are providing services, leading to less than ideal fidelity. The number one piece of advice they would pass on to other clinics is to budget for training beyond the first year. Given the high rate of turnover, resources for training is a continuous need.



### YALE STEP CALL NOTES

August 19, 2015

#### **Participants:**

Jessica Pollard, Ph.D., Yale STEP David Shern, Ph.D., NASMHPD Mihran Kazandjian, NRI Kristin Neylon, NRI

#### **Discussion:**

- When evaluating the health of an entire program, Yale STEP looks broadly at the
  percentage of clients who are working or in school. They use the Department of Labor
  standards for vocational engagement. They also look at symptom remission, and other
  cardiovascular outcomes (including weight, smoking, and substance abuse). The
  program looks broadly at how well clients are doing overall, rather than day-to-day
  progress. Benchmarks are used in terms of functional outcomes, such as school and
  employment standards. Clinical measures are in place to evaluate positive symptoms.
- Yale STEP collects data on individuals through diagnostic instruments like the SCID and PANSS. The SCID is used for initial evaluation, and the PANSS is used to assess symptoms throughout treatment. The PANSS is administered at baseline and every six months for the research side. During weekly meetings, PANSS scores are not examined because clinical staff are familiar with the criteria and use "APGAR" scores of positive symptom remission and whether the client is working in school to help determine if a person is benefiting from services. Level of engagement in services is also discussed (i.e., in what interventions are they participating). Based on these discussions, the program determines if adjustments need to be made to treatment. A thorough review of patients is completed at landmark points in time (e.g., one month and every six months post-admission).
- The STEP Program relies on the SIPS to establish presence of active psychosis and symptom onset. In the past, the program implemented the SOS, but has stopped using it. The SIPS helps the program establish the duration of untreated psychosis. A confidence rating scale is used to ensure a close estimate of when onset is determined. The SIPS helps identify that consumers are in the appropriate clinic (Psychosis Risk or First Episode). IRB has approved the use of this tool. When people present to the program at the beginning, clinicians work to debunk myths associated with psychosis, and ensure that the person is comfortable with treatment. These make a huge difference in what people are willing to share on the diagnostic and intake forms. If a client feels the clinician is uncomfortable, they are less willing to admit to difficulties and share their experiences, so it is particularly important clinicians convey their familiarity and comfort with psychosis. The SIPS asks "softer" questions that help achieve a level of patient-clinician comfort that other instruments may not afford. The SIPS also offers clear criteria on how to score.

- Pathways to Care is highly specific to the duration of untreated psychosis reduction campaign they are working on. They use the Diana Perkins scale, and have modified it with her permission. The scale is very in depth about health seeking behaviors and is not often used clinically. Clinically, they will ask the consumer where they have received treatment so they can seek treatment records. This instrument does help understand where people seek help from a public health perspective, and help identify where to target outreach efforts. (Note: STEP does use the information on prior treatment from this interview in the initial evaluation summary and in clinical discussion, but not the details of their help-seeking efforts that are covered in this interview.)
- As a psychologist, Dr. Pollard would not implement the SCID in routine clinical assessments (this is used for research evaluations). It is helpful to set up a framework for clinical assessment, but many clients they work with will not tolerate that level of structure in clinical appointments.
- The information the program collects is important, and the scales are useful in providing good things to know, but it is also important to spend time working on bedside manner. It is a huge part of the engagement strategy. Engagement is the most important part of the work the program does.
- The Premorbid Adjustment Scale helps clinicians know what clients' lives were like before they presented to the program. It helps them determine what baseline might be. It is a very useful scale.
- The Calgary Depression Scale is quick and useful and should be kept.
- The Heinrichs Quality of Life Scale is not especially useful for the population served by the Yale STEP program. It is a bit outdated in terms of items, and does not reflect all the ways their clients might engage with daily living.
- A relatively new addition to the list of instruments used by the program is the Aggression Scale. The program is interested in looking at criminal justice outcomes. There is a safety interest at the clinic. The first trial recognized improvement in vocational engagement, and a decrease in hospitalizations in the first trial; they are looking for the trifecta of reduced criminal justice involvement. Safety of the clients and the clinicians is the number one priority. Suicidality and aggression scales are useful.
- The Habits Scale includes information about how many cigarettes per day a person consumes, and quantifies substance abuse including smoking, alcohol, illicit drugs, and caffeine. Also helps the program evaluate cardiovascular risk.
- Alcohol/Drug Use Scales: Evaluates criteria related to abuse and dependence: Do clients meet criteria for abuse and dependence? The tool reviews each substance and allows for ratings on five points from abstinence to dependence. When reviewing patients at 6 and 12 months, look to see if there is a change.
- Cannabis Scale: There is a fair amount of cannabis use among the treatment population. This scale includes age at first onset as well as past cannabis use. It is a rating scale and includes how often they use or have used, if they use in social isolation or in social settings. It is more in depth than the other substance use instruments because this is a big issue for their population.
- SF-36: Not very confident in the effectiveness of this scale.

- One of the goals on the research side has been cost effectiveness. They use the SURF to make sure they can have cost estimates to show savings/disease burden. A report about these outcomes is in press. Data show a decrease in hospital days and more vocational engagement. The cost estimate of services is inexpensive. The program is in the process of calculating a case-based rate. Looking strictly at economic impact of the program is impressive.
- Program does monitor medication use over time. They try to get pharmacy data for that. It is useful in clinical decision-making, as it helps determine if the client has had adequate trials of different medications to see if a different class of medication should be used.
- LUNSORS is a side effect scale that is useful to the program.
- MATRICS: this scale helps evaluate level of functioning and IQ. It has been surprising how low some of the IQ scores have been. Has spurred the discussion about implementing a more standard cognitive battery beyond what they are collecting on research.
- Regarding data collected by the program: There are a few different layers. The STEP
  program uses the APGAR score, which is a rough cut of how people are doing in terms
  of whether the treatment is working. Each week, the team goes through a "Lightning
  Round" to run through these ratings verbally. This is the first layer. Another piece is the
  assessment data sheet that is entered into REDCap, which is an electronic database
  used to compile data for research. The clinical and research teams have access to the
  data submitted to RedCAP; however, it is analyzed differently on each side.
- An attending psychiatrist was recently awarded a foundation grant to create a clinical dashboard. Data tend to be unwieldy and difficult to monitor over time without a database organization tool. With this new tool, clinicians should be able to monitor data on clients.
- Yale STEP relies on pharmacy data for medications. They fax releases to the pharmacy, in turn the pharmacy sends printouts. A beloved research assistant enters these data into a database. Having a research assistant is one of the luxuries of being so closely tied to the research arm of the university. Also provides time to review and access data that other programs may not be able to dedicate time or resources to.
- For "STEP 2.0," Dr. Pollard would like to establish benchmarks around incidence and characteristics of population.
- Program uses Family Focused Therapy, a new addition to the program when it re-launched in 2013. FFT is useful because it is delivered to individual families with a skill-building component. Has all the elements except for group, along with a teaching component for different skills and communication. Had previously used the Multi-Family Group model, but had difficulty in terms of attendance and engagement.

The engagement scale is completed during rounds. It was originally developed for ACT teams, and is a little clunky and difficult to rate. Clinicians are not fond of this instrument. Engagement can be a difficult domain to evaluate, because someone could appear through data to be really engaged, but actually are being dragged to every appointment and do not want to be receiving services and are not meaningfully participating.

### **Other Comments:**

- The program is less interested in fidelity than outcomes. If your clients are not achieving outcomes, then the services do not matter. They have deliberately stayed away from a fidelity-driven approach so they can change things as needed, rather than adhering to a specific fidelity rating. There has to be a balance.
- Each week the program contributes to an activity log for each client explaining what activities the client participated in that week (e.g., FFT, Medication Management). This helps the program monitor what they do, and allows for an evaluation of fidelity. They do have values and principles within the clinic, but try not to get too concerned with perfect fidelity ratings. There is balance in outcome.

