

Regulations Implementation Project Subcommittee Meeting
February 23 and 24, 2016
Access and Linkage Requirements and
Measurement of Duration of Untreated Mental Illness

Q&A

Early Access and Linkage: Why it Matters

A driving goal of the Mental Health Services Act (MHSA) is a significant reduction in the number of Californians who “fall through the cracks,” and are unable to access timely and appropriate mental health services. In line with decades of research and clinical best practices in early intervention, the Act underscores the importance of a community mental health system capable of reaching and supporting Californians as soon as possible following the onset of psychiatric symptoms with the aim of preventing long-term disability and prolonged suffering. The Prevention and Early Intervention (PEI) regulations both reinforce and help operationalize these goals along with a series of performance monitoring strategies and requirements designed to gauge their success.

What is “Access and Linkage” and what is required of counties under the new regulations?

Counties are required to integrate “Access and Linkage” strategies into all PEI funded programs and services, and to operate at least one “stand-alone” access and linkage program. (Examples of stand-alone programs include telephone help lines, mobile crisis teams, or a county triage center.) The intent of “Access and linkage” strategies and programs is to help ensure that community members with “severe mental illness” who come in contact with any PEI program, including one-time public outreach efforts, are able to access the treatment they need. Programs may refer clients internally (e.g. assess at an early intervention program and then provide services within the same program) or refer externally (help clients access services in another PEI program, or through other funding streams, including MHSA-funded Community Support Services (CSS) programs).

Do the new regulations allow braided funding streams?

Nothing in the regulations states that counties cannot braid monetary streams in order to fund services (such as a one-stop triage program that spans PEI and CSS). Because reporting mandates are specific to each funding stream, however, a braided program must determine some way of distinguishing persons served under PEI (and subject to PEI reporting mandates) versus CSS. For instance, a county might collect and report access and linkage (including duration of untreated mental illness (DUMI)) data on all untreated serious mental illness (SMI) cases assessed through a braided program, or track all incoming referrals from PEI-funded programs.

What data must PEI programs now collect under the new regulations?

For any individual with serious mental illness (SMI) who engages with or participates in any PEI program, the County must track:

- *Number of individuals with SMI referred to treatment, and the kind of treatment to which the individual was referred;*
- *Number of individuals who followed through on the referral and engaged in treatment, defined as the number of individuals who participated at least once in the program to which they were referred;*
- *Average duration of untreated mental illness for individuals without prior treatment for the SMI for which they were referred (see below);*

- Average interval between the referral and participation in treatment, defined as participating at least once in the treatment to which referred.

Who (what clients) would the PEI Access & Linkage data reporting requirement apply to?

The PEI reporting requirement applies to any individual seen or assessed within a PEI program and then referred for new, additional and/or more intensive ‘medically necessary’ treatment on the basis of symptoms or behavior consistent with a “severe mental illness”. The requirement applies to clients first engaged through a stand-alone access and linkage program or routed through the (mandatory) access and linkage strategy embedded within every PEI program. Clients who are treated in the same PEI program at which they receive their first assessment also are included in the reporting mandate.

Examples of who the requirement would apply to:

- An individual in a PEI stigma reduction or outreach program who presents with SMI and who is consequently referred to a PEI Early Intervention Program, CSS program or MediCal/private pay services;
- An individual in a prodromal prevention program who “converts” to full-blown psychosis and is then referred for more intensive services through PEI Early Intervention, CSS, MediCal, etc.;
- An individual with SMI first assessed at a clinical PEI program (for instance an early intervention in psychosis program, or prodromal prevention program) and then treated in that program;

Examples of who the requirement would not apply to:

- Any individual with mild or moderate mental illness.
- An individual with SMI participating in PEI-funded programs but who is already receiving medically necessary treatment.

Who is charged with collecting and reporting Access & Linkage data?

The PEI Access and Linkage reporting requirement is a county-level mandate. It is up to each county to develop specific protocols or processes for obtaining the information required. Variations in how PEI programs are administered and delivered will almost certainly influence the strategies adopted in particular counties.

Duration of Untreated Mental Illness (DUMI)

What is the measurement of DUMI as required by the new regulations expected to accomplish?

A large body of research attests to the enduring impact of duration of untreated serious mental illness on long-term outcomes, including functional recovery. County-wide DUMI measurement for all individuals presenting in PEI programs with untreated severe mental illness is expected to serve as a key performance indicator. Over time, this data will help counties improve the capacity of PEI programs to successfully identify individuals with untreated SMI as soon as possible following symptom onset and effectively link them into treatment.

What is the “untreated mental illness” in question?

The DUMI reporting requirement narrowly applies to the “severe mental illness” for which an individual with untreated SMI has been or is being referred. Thus if a given client had a 10 year history of moderate depression, but was referred on the basis of previously untreated recent onset psychosis, DUMI would be measured for the psychotic disorder, not for depressive symptoms.

Who would the “duration of untreated mental illness” reporting requirement apply to?

In contrast to other Access & Linkage data reporting requirements, DUMI applies only to individuals who are served by PEI-funded programs with previously untreated severe mental illness at the point at which they first encounter PEI services.

Examples of who the requirement would apply to:

- *An individual who shows up at an outreach or stigma reduction program with untreated SMI and is referred to clinical services either within or outside of PEI.*
- *An individual with SMI served by a PEI-funded clinical prevention or early intervention program who, when treatment commences, has not been previously treated for that SMI.*

Examples of who the requirement would not apply to:

- *Any individual participating in a PEI program with a non-severe (mild or moderate) mental illness, even if untreated.*

How would DUMI be measured?

DUMI measurement is left up to each county. Each county may use separate metrics for different diagnoses (e.g. separate measures for “duration of untreated psychosis,” “duration of untreated mania,” “duration of untreated major depression” etc.) or to use a single common measure. Under the regulations counties may rely on either self-report or family report, however, counties also may utilize additional triangulation strategies or cross-reference clinical or medical records.

Would self-or family-report DUMI yield meaningful data? What about difficult to determine cases such as clients with compromised insight who have been living on the streets for decades?

Regardless of the domain, there is always some risk of inaccuracy for all self-report data, including recall biases for individuals asked to remember events decades prior or persons in altered mental states. These challenges hold for multiple domains of clinical diagnosis and outcomes measurement, however, and are not unique to DUMI. In many countries outside the United States, including Canada and the United Kingdom, self-report DUP (duration of untreated psychosis) metrics are used outside of research settings as part of broader performance monitoring or benchmarking strategies and a variety of DUP instruments and assessment strategies have been developed to help non-research clinicians elicit more accurate information from clients.