Clinically Complex Long-Term Enrollees: A Review of the Data

Chelsea Shepherd, LCSW; Dr. Katy Stratigos, MD; Calvin Muza, MSW; Oruada Ogbu, MSW

Objectivity and Aims

START is a short-term program, however currently we support a high number of long-term enrollees. Some of this is backlog due to the pandemic (difficulty accessing non-START resources, etc) but about 7% of our caseload consists of Long-Term Enrollees who remain in crisis.

Our aim is to evaluate the data to find what patterns emerge, so that we can better support, stabilize and advocate for the people we support.

Definition: Long-Term Enrollee in Crisis (LTE-C)

An individual enrolled in START for over 3 years who has remained a Tier 4 on 2 consecutive BPRIs (a NYS evaluation of stability).

As of 3/05/2024, 13 individuals met this criteria. Please note that members supported by START and their level of stability fluctuates.

LTE-C START Plan Level of Involvement			
Level 4	Level 3	Level 2	Level 1
6	2	3	2

Abstract

Predictors of chronic mental illness in individuals with intellectual disabilities include a combination of demographic, health, and psychosocial factors. Women and older adults have higher rates of mental ill-health in this population. Additionally, low family socioeconomic status and having a single biological parent as a caregiver are significant predictors.[1-2] Comorbidity is yet another predictor of chronic mental illness: the presence of chronic health conditions such as urinary incontinence and hearing impairments, are associated with increased risk of mental illness. More severe intellectual disabilities and co-occurring conditions like autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) also elevate the risk.[3][5] Certain genetic syndromes, such as Down syndrome and fetal alcohol spectrum disorder, have specific psychiatric profiles that influence the risk of mental illness.[2][5]
Stressors such as changes in residence, family problems, or trauma, significantly predicts mental health issues. Individuals with ID are also at increased risk for trauma and abuse, which can trigger or exacerbate psychiatric symptoms. [2-3]
Environmental factors: Sensitivity to environmental changes, such as variations in routine or inappropriate educational placements, can contribute to psychiatric symptoms. The transition from pediatric to adult services is another period of increased risk for mental health problems.[2][6] Not only transitions, but the type of accommodation and support an individual receives has major impact on their ability to stabilize [2-3].
Existing research, limited as it may be, demonstrates that the reason that any given individual with IDD is chronically mentally ill is likely multifaceted and may include demographic, health, psychological, environmental and genetic factors. A holistic, multidisciplinary approach to care, including specialized services for particular subsets of the IDD population (complex PTSD, complex medical profile, appropriate housing and community-based supports) that communicate effectively with each other would best serve this population.

Who *is* getting better?

Former LTE-Cs

Case study 1

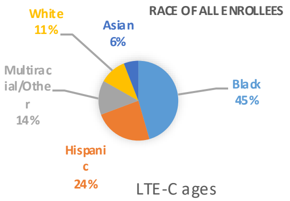
- African American woman in her 30s with a long history of foster care, residential care and years-long psychiatric hospitalizations.
- LE's greatest struggles come from her fixed insistence that she is pregnant, and her frustration at the lack of medical care she is receiving for her baby (she is not pregnant).
- Mild/Moderate Intellectual Disability, Autism Spectrum Disorder, and numerous psychiatric diagnoses including schizophrenia and schizoaffective disorder.
- LE reached stability when she moved to a residence that acknowledged her "pregnancy" and moved on rather than confront her on it.
- This enabled LE to feel loved and cared for, and left her willing to participate in activities that she enjoys. She is finally enrolled in a day hab after many years of waiting!

Case study 2

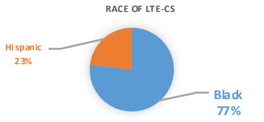
- African American woman in her 20s with a history of residential care and later abandonment by her adoptive family.
- Mild/Moderate Intellectual Disability, Autism Spectrum Disorder, and numerous psychiatric diagnoses including schizoaffective disorder, bipolar disorder, and borderline personality disorder.
- START conceptualization was Complex PTSD.
- START partnered with AP's residence to help bring her to activities she likes now rather than wait until she is "stable enough."
    - Loves the nail salon, hair salon, visiting pet stores to see dogs.

Demographics

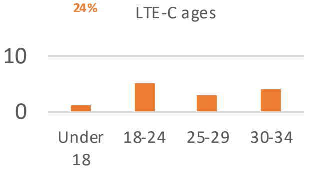
Race



Black/African American people are already overrepresented in NY START (45% of enrollees vs. 20% of NYC population) HOWEVER, they make up 77% of LTE-Cs.

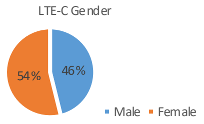


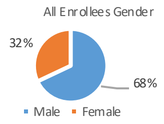
Age



- **None of our LTE-Cs are over 35**
- **21% of current enrollees are over 35**
- **Mean age of START adult is 30 years**

Gender



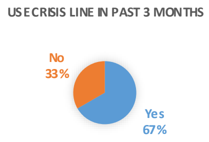


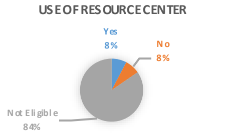
75% of LTE-Cs enrolled over 4 years are female

Our team does not currently support anyone who does not identify as either female or male

Use of Services

Use of START Services

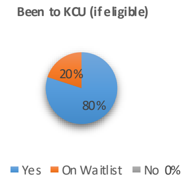




2 not Eligible for Resource Center due to age

9 not Eligible for Resource Center due to state restrictions

Use of Linkage Svcs.



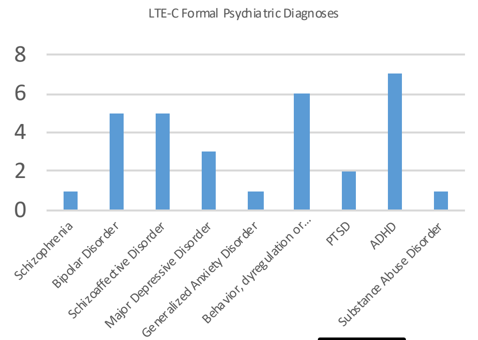
KCU: An inpatient psychiatric unit for adults with comorbid behavioral health and IDD needs

ETU: Extended Treatment Unit, a medium-term residential treatment facility (trauma-informed care, high staffing ratios)

Note: the "yes" was at ETU currently

Diagnoses

Psychiatric



Over-representation of ADHD – 53% of LTE-Cs have ADHD vs. about 6-16% of children in USA (https://www.cdc.gov/adhd/data/index.html)

Under-representation of PTSD – 15% of LTE-Cs vs. an expected 30-80%

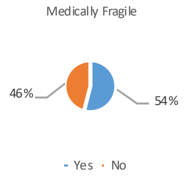
- **START conceptualizes 84% of LTE-Cs have PTSD**

START Conceptualization agrees with formal diagnoses for 30% of LTE-Cs

- 3 males with ADHD diagnoses
- 1 male with Substance Use Disorder diagnosis

Medical

Medically fragile: having 2 or more chronic medical conditions and/or one severe medical condition (epilepsy, genetic disorder, serious cardiac condition)



Trauma

4 with suspected or known Physical Abuse history
4 with suspected or known Sexual Abuse History
6 with a history of foster care (familial/non-familial) or childhood institutionalization
8 with history of Other Significant Trauma (medical trauma, loss of parents, significant move)

People in at least 1 category: 84%
People who fell into 2 or more categories: 53%

Recommendations

- In-depth review of **PERMA** for LTE-Cs
- **Further explore ADHD** and it's impact on LTE-Cs - were these individuals able to access best medicines during the shortage?
- More Collaboration with the system to **support PTSD and ADHD**
- Investigate why the roles of **race and gender have such an impact**. Investigate socioeconomic and geographic causes.
- Explore the role of **polypharmacy** in LTE-Cs
- Deeper dive into **medical complexities.** Explore **access** to medical care (already exploring gyn)
    - Assess for **unidentified or identified pain** as a contributor to psychological distress
    - What is the impact that the lack of specialized **Women's Health** has on the **over-representation of women** amongst LTE-Cs?
    - Explore **stronger healthcare partnerships** outside of Premier Health (our own clinic).

Findings

<u>New York State and NCSS have different means of measuring stability, which effects long-term enrollment</u>

<u>Predictors of Long-Term Enrollment:</u>

- **Race (black)**
- **Diagnosis**
    - **ADHD:** Particularly in males who also have a trauma history
    - **Missed PTSD:** Missed/misunderstood trauma is gender-specific (female) and often diagnosed at Schizoaffective disorder or impulse control/mood dysregulation disorder
- **Gender (female)**

<u>We lack a means to evaluate a system's openness to collaborating with START</u>

- For both Case Studies (and in other examples we have seen) it took significant time for residences to support PERMA (or in both case examples, a move to a more open and willing residence)
- In some instances of LTE-Cs, this is an identified barrier to stability however is difficult to capture

How We Have Used this Information

- Used the LTE-C list to inform our King's County admissions with an emphasis on ETU referrals for those with missed/unaddressed trauma
- Further increased our emphasis on finding PERMA to systems
    - Use de-identified cases in presentations to demonstrate that this model can work on the most complex individuals
- Shared the findings with OMH to advocate for increase in services for IDD Trauma Informed Care

Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. The British Journal of Psychiatry: The Journal of Mental Science. 2007;190:27-35. doi:10.1192/bjp.bp.106.022483; Siegel M, McGuire K, Veenstra-VanderWeele J, et al. Journal of the American Academy of Child and Adolescent Psychiatry. 2020;59(4):468-496. doi:10.1016/j.jaac.2019.11.018; Smiley E, Cooper SA, Finlayson J, et al. The British Journal of Psychiatry: The Journal of Mental Science. 2007;191:313-9. doi:10.1192/bjp.bp.106.031104; Hsieh K, Scott HM, Murthy S. American Journal on Intellectual and Developmental Disabilities. 2020;125(1):49-63. doi:10.1352/1944-7558-125.1.49; Arnold SR, Huang Y, Srasuebkul P, et al. The Australian and New Zealand Journal of Psychiatry. 2025;48674251324824. doi:10.1177/00048674251324824; New Research; Marquis S, Lunsky Y, McGrail KM, Baumbusch J. Research on Child and Adolescent Psychopathology. 2024;52(7):1147-1156. doi:10.1007/s10802-024-01174-0. New Research.