NEW YORK STATE | NYSTART Systemic, Therapeutic, Assessment, Resources and Treatment

An initiative of the New York State Office for People With Developmental Disabilities

NYSTART Region 4 Tri-Borough

September 2016 – March 2018

Initial Report

Prepared for

The New York Office for People With Developmental Disabilities

Prepared by

The Center for START Services

THE CENTER FOR START SERVICES

On May 31, 2018

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START, which stands for Systemic, Therapeutic, Assessment, Resources & Treatment, is a comprehensive model of service supports that optimizes independence, treatment, and community living for individuals with intellectual/developmental disabilities (IDD) and behavioral health needs.

The Center for START Services, a program of the University of New Hampshire Institute on Disability/UCED, is a national initiative that strengthens efficiencies and service outcomes for individuals with and behavioral health needs in the community.

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Introduction

This report offers a comprehensive summary of services provided by the NYSTART Region 4 Tri-Borough team for FY2017/2018. The analysis includes assessment of outcomes as well as fidelity measures for the START model. Recommendations reflect the results of the analysis and service provision to date.

This report is separated into five sections:

- FY2017/2018 Enrollment Trends
- Characteristics of Persons Served (demographics and clinical trends)
- Emergency Service Trends
- START Clinical Team Services

The NYSTART Region 4 Tri-Borough program will develop an action plan based on recommendations from the analysis in collaboration with the Center for START Services and NYS OPWDD.

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NYSTART Region 4 Tri-Borough Program

Program Background

NYSTART Region 4 Tri-Borough (TB) began operations in September 2016 and has served a total of 260 individuals since that time. It currently represents about 22% of the active NYSTART population (see figure 1). All NYSTART programs provide lifespan services (serving individuals aged 6 and older), and currently children under the age of 18 make up 32% of the Tri-Borough caseload. This is identical to the NYSTART Richmond Kings (RK) program, which covers the boroughs of Brooklyn and Staten Island in New York City, and is also consistent with START programs nationally (see figure 2).

The following is a list of NYSTART programs by region:

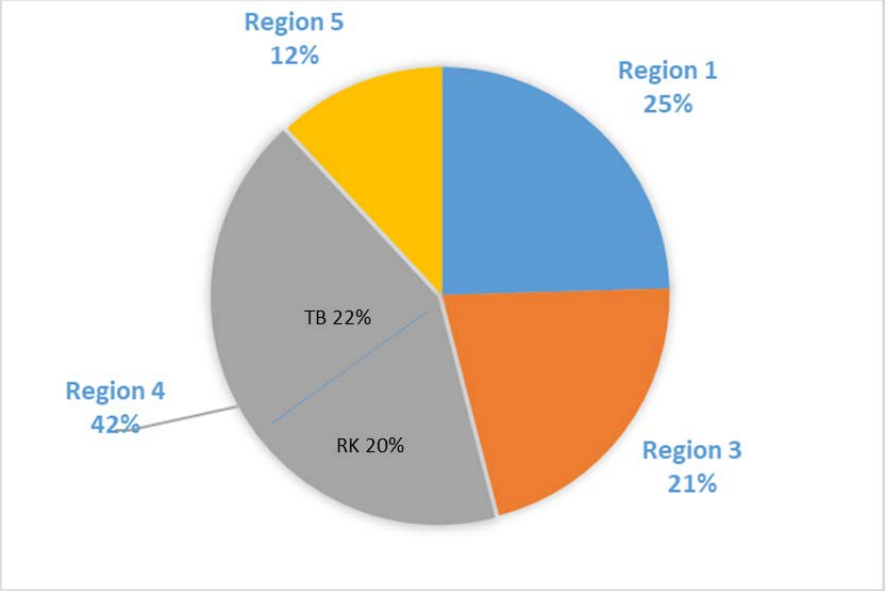
Region 1- Western NY and Finger Lakes

Region 3- Capital District, Taconic and Hudson Valley

Region 4- New York City (Tri-Borough and Richmond Kings)

Region 5- Long Island

Figure 1: Active NYSTART Population by Region (n=866)



*Region 5, NYSTART Long Island, is very newly formed and these proportions are likely to change significantly over the next year.

Figure 2: Percent of Active START Population by Age Category for Region 4 Tri-Borough and Other START Programs

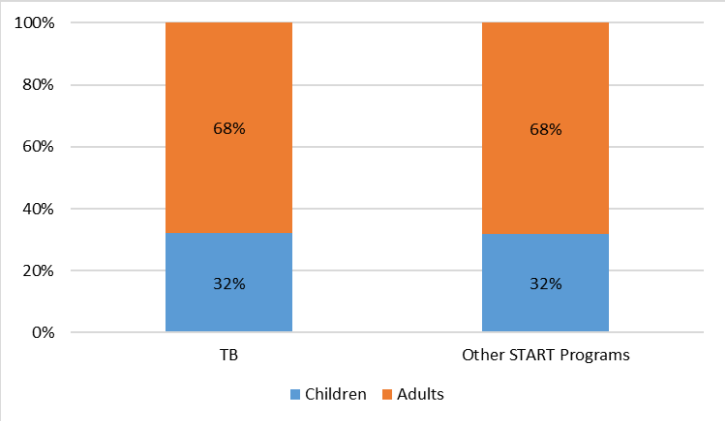
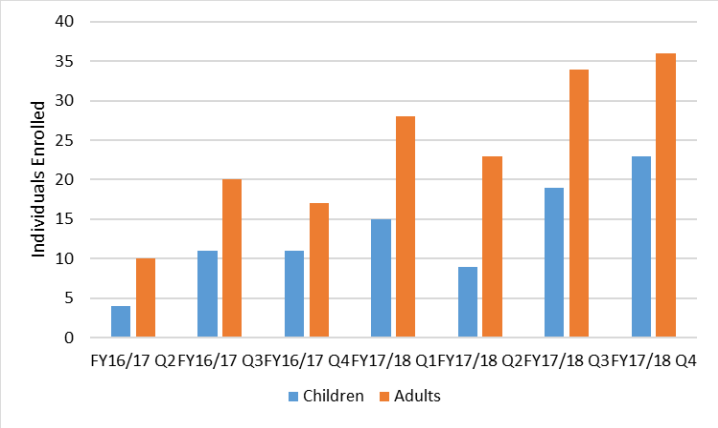
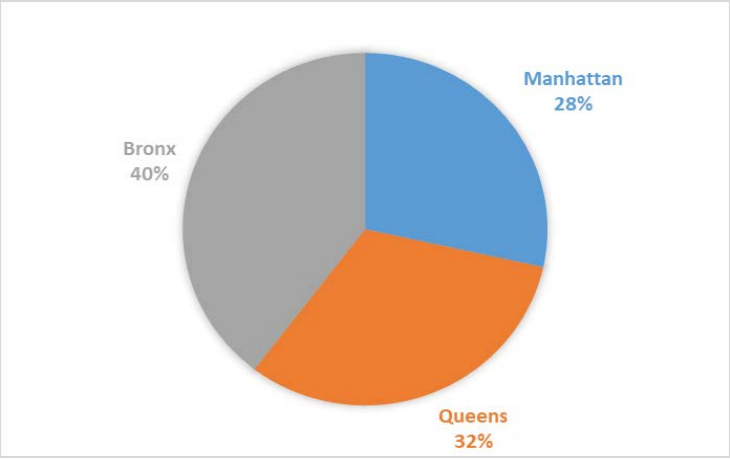


Figure 3: Number of Individuals Enrolled in Region 4 Tri-Borough by Quarter (n=260)



The Tri-Borough START program has been steadily growing, and will continue to grow as coordinator vacancies are filled.

Figure 4: Number of Individuals Enrolled in Region 4 Tri-Borough by Borough (n=260)



Findings

The following sections provide an analysis of enrollment, demographic and service outcome data for the Region 4 Tri-Borough program since operations began in September 2016 (September 1, 2016- March 31, 2018). This is the first comprehensive report for Region 4 Tri-Borough.

All descriptions of enrollment trends, characteristics of persons served, emergency service trends, and service outcomes of those served by Region 4 Tri-Borough are based on data entered into the START Information Reporting System (SIRS) by program staff.

Section I: FY 2017/2018 Program Enrollment

Data below reflect all individuals served by Region 4 Tri-Borough during this report period.

Table I.A: Census Summary

Variable	Children	Adults
Total Served during reporting period N(%)	92 (35%)	168 (65%)
Individuals inactivated	31	39
Stable functioning	3 (10%)	10 (26%)
Moved out of START region	4 (13%)	6 (15%)
No longer requesting services	18 (58%)	16 (41%)
Inappropriate for services	-	3 (8%)
No contact	6 (19%)	3 (8%)
Long term placement	-	-
Incarcerated	-	1 (3%)
Unreported	-	-
Active Caseload at the end of reporting period	61 (32%)	129 (68%)

Table I.B: Sources of Referral

Variable	Children	Adults
N	92	168
Referral Source (%)		
Case Manager	59%	51%
Emergency Department/mobile crisis	10%	5%
Family Member	9%	5%
Residential/Day Provider	-	15%
Hospital/ID Center	4%	6%
Mental Health Practitioner	4%	4%
Other (Transfer case, Behavior Analyst, School)	14%	14%
Missing	-	-

Table I.C: Reasons for enrollment (more than one option can be selected)

Variable	Children	Adults
N	92	168
Most Common Reasons for Enrollment (%)		
Aggression	97%	89%
Family Needs Assistance	66%	46%
Risk of losing placement	8%	17%
Decreased Daily Functioning	13%	23%
Diagnosis and Treatment Planning	10%	14%
Mental Health Symptoms	23%	45%
Leaving Unexpectedly	24%	25%
Suicidality	2%	11%
Self-Injurious Behavior	37%	23%
Sexualized Behavior	14%	15%
Transition from Hospital	8%	8%

Summary

- The Region 4 Tri-Borough team provided services to 260 individuals since program inception (FY 2017/2018), including a large cohort of children (n=92). As with most START programs, the majority of referrals were received from case managers. However, there were referrals from a wide variety of sources. Efforts are ongoing to educate all stakeholders to encourage referrals of all who may benefit from having START team involvement.
- Individuals remain active in the Region 4 Tri-Borough program for fewer months on average than is seen in other START programs (looking at national trends and averages) suggesting that people who could benefit from START services are disengaging from the START team. There was a concerning rate for disengaging from START reported this FY for both children and adults. It will be important to address this in FY 2018/2019 (see recommendations). However, it is suspected that these high rates were primarily related to a large turnover in staff, especially in key leadership roles. Recent data suggest this is already improving.
- Like all START programs, the primary reason for referral is the presence of aggression. The number of individuals referred due to concerns about their mental health symptoms is low in comparison with other programs at similar stages of development. This highlights the need for education of system partners on mental health symptoms in IDD. This trend will be monitored going forward.

Recommendations

- Closely study all occurrences of individuals enrolled in START who are made inactive due to disengaging and develop processes and new approaches to retain individuals in the program who are seen as potentially benefitting from the services and inform them of the supports available.
- Implement steps and review data quarterly to ensure rates of inactivation of cases due to "no longer requesting services" is <10% by the 3rd quarter of FY 2018/2019.
- Continue to conduct outreach, consultation and training to increase the skills of clinicians and others in the local system of care in regard to the multiple influences on behavioral health challenges.

Section II: Characteristics of Persons Served

Demographics

Section II of this report provides demographic and diagnostic trend data for all individuals served by Region 4 Tri-Borough (N=260) since program inception (September 1, 2016-March 31, 2018). When relevant, the Region 4 Tri-Borough population is compared to the national START population from other lifespan programs.

Table II.A: Age, gender, race, level of ID, and living situation of active cases

Region 4 Tri-Borough	FY17/18 (n=260)	
Variable	Children	Adults
N	92	168
Mean Age (Range)	14 (6-17)	30 (18-65)
Gender (% male)	80%	64%
Race		
White/Caucasian	16%	27%
African American	30%	38%
Asian	13%	5%
Hispanic/Latino	23%	15%
Other (includes Arab, Guyanese, Bangladeshi, Haitian and unspecified)	12%	12%
Unknown/Missing	5%	4%
Ethnicity (% Hispanic)	44%	38%
Level of Intellectual Disability (%)		
No ID/Borderline	2%	3%
Mild	38%	39%
Moderate	39%	40%
Severe-Profound	13%	14%
None Noted	7%	4%
Missing	1%	-
Living Situation (%)		
Family	100%	52%
Alternative Family Living (foster family)	-	-
Group Home and Community ICF/DD	-	35%
Independent/Supervised	-	7%
Psych. Hospital/IDD Center	-	5%
Other (Jail, Homeless, "Other")	-	2%
Missing	-	-

Summary

- Overall, many of the demographic factors are similar across START programs, though a few differences are demonstrated in this data set including a somewhat higher proportion of male versus female child enrollees and the lower rate of adults residing in group home settings. All of the children enrolled in the time period covered were living with family which is remarkable. In addition, half of the adults served also reside with family. This presents a unique opportunity and supports an overarching goal of START to help families stay together and for individuals to remain with natural supports when possible.
- Similar to Richmond Kings, its sister Region 4 START program, the Region 4 Tri-Borough team serves a population that is more ethnically and racially diverse than other more rural START programs. START is committed to increasing the cultural competence of all program staff, and have developed specialized training opportunities (see section below regarding outreach and training activities). A recent published report regarding emergency services use and START services found that African American enrollees were more likely to have experienced an inpatient psychiatric hospitalization in the year prior to intake into START services.[1]

Recommendations

- Participate in national training opportunities offered regarding cultural competence as applied to work with individuals with IDD and then develop and deliver training to community partners to address this topic.

[1] Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalization among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research*, *60*(12), 1153-1164.

Mental Health and Chronic Health Conditions

Table II.B: Mental health conditions

Variable	Children	Adults
N	92	168
Mental Health Conditions (%)		
At least 1 diagnosis	91%	86%
Mean Diagnoses (range)	1.7 (1-5)	2.0 (1-5)
Most Common MH Conditions (%)		
Anxiety Disorders	2%	9%
ADHD	35%	19%
ASD	82%	44%
Bipolar Disorders	6%	25%
Depressive Disorders	2%	10%
Disruptive Disorders	15%	41%
OCD	8%	9%
Personality Disorders	-	5%
Schizophrenia Spectrum Disorders	4%	26%
Trauma/Stressor Disorders	1%	3%

Figure II.A: Frequency of most common mental health conditions for enrolled children (trends across START)

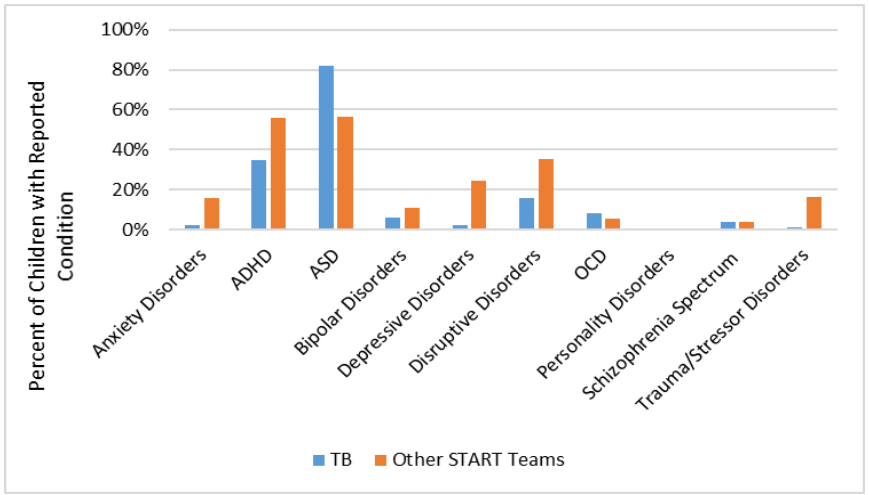


Figure II.B: Frequency of most common mental health conditions for enrolled adults (trends across START)

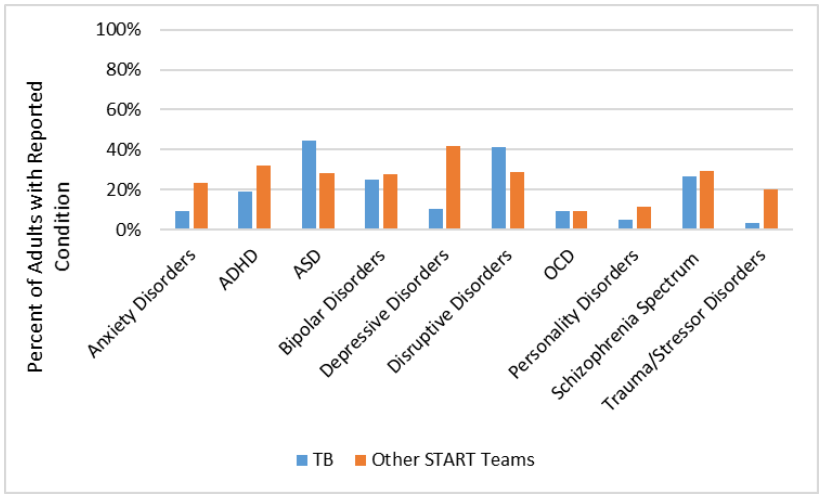


Table II.C: Chronic medical conditions

Variable	Children	Adults
N	92	168
Medical Diagnosis (%)		
At least 1 diagnosis	37%	47%
Mean Diagnoses	1.3 (1-4)	1.8 (1-6)
Most Common Medical Conditions (%)		
Cardiovascular	9%	16%
Endocrine	3%	27%
Gastro/Intestinal	12%	10%
Genitourinary	-	5%
Immunology/Allergy	-	4%
Musculoskeletal	6%	5%
Neurologic	18%	35%
Obesity	6%	15%
Pulmonary disorders	26%	11%
Sleep Disorder	-	5%

Figure II.C: Frequency of most common medical conditions for enrolled children (trends across START)

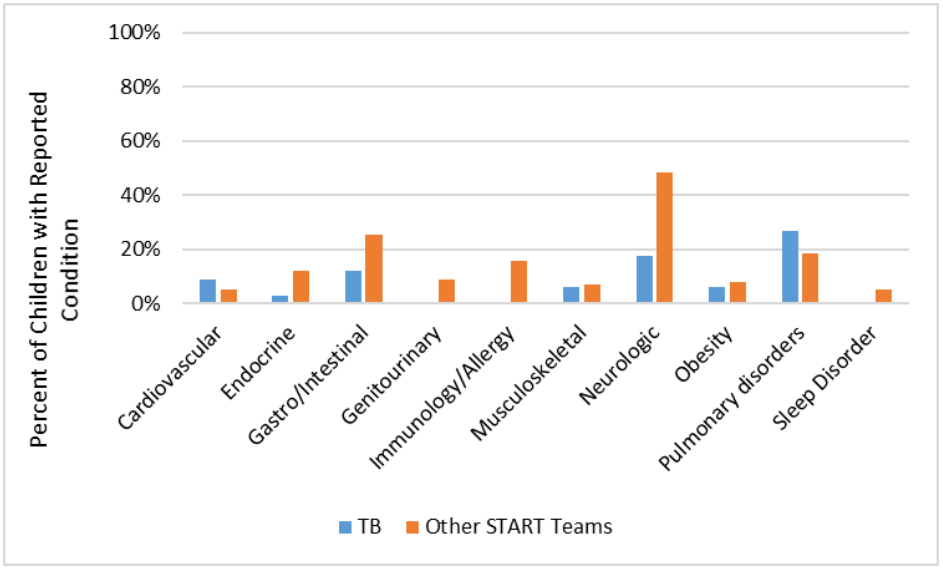
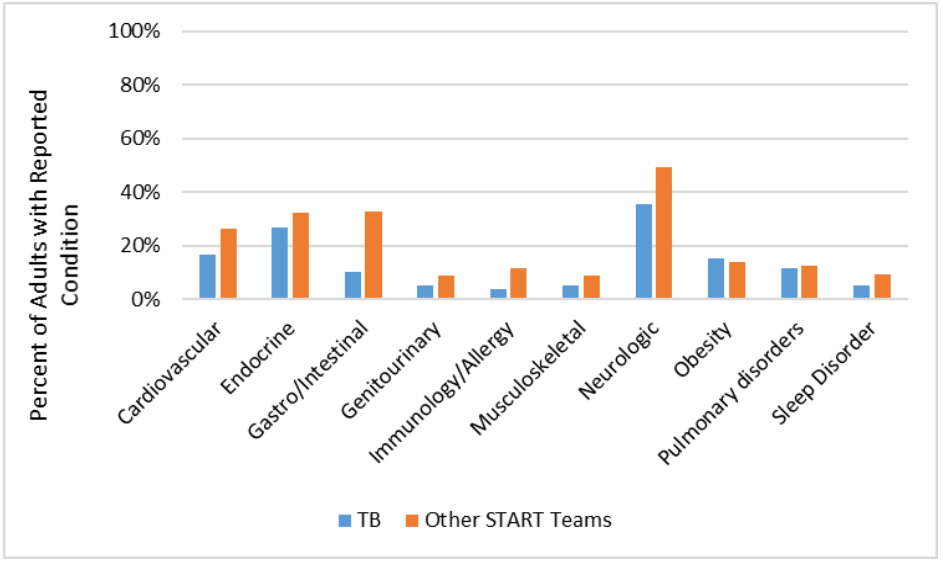


Figure II.D: Frequency of most common medical conditions for enrolled adults (trends across START)



Summary

- Most individuals served by the Region 4 Tri-Borough program had a psychiatric diagnosis reported at intake. Many individuals had more than one, which is similar to other START programs.
- Among children, the low rates of reported anxiety disorders are common when a START program is fairly new in a region. This often reflects a likely area of educational need in the local system of care. Eighty percent of the children served have a diagnosis of Autism Spectrum Disorder (ASD). The most common psychiatric concern reported for youth with an ASD is some form of an anxiety problem (i.e. phobias) or anxiety disorder (generalized anxiety, panic). The rates reported here are significantly lower than what would be expected.
- Reported rates of health problems was lower than expected based on the current research as well as rates in other START programs. In clinically referred populations of people with IDD and behavioral health challenges, problems such as Gastroesophageal Reflux Disease (GERD) and constipation are generally identified in 30-60% of cases. Obesity is also reported at lower than expected rates. Children with ASD in particular have reported rates of seizure disorders of around 25-30% (in general surveys not specific to those with high rates of psychiatric comorbidity). Youth with ASD as well as other IDD often also have other neurological diagnoses (i.e. cerebral palsy, other congenital neuromotor syndromes).
- The report of 26% of children having pulmonary conditions reflects a high rate of asthma that is higher than more rural START programs, but less than some reports from cities. Childhood asthma and mental health concerns have been linked in a number of investigations.[2]
- The elevated rate of endocrine health concerns in adults may stem from Metabolic Syndrome and Diabetes Type 2, which in turn may be associated with the psychoactive medication regimens that often include antipsychotic drugs.
- START programs are dedicated to the importance of promoting both physical and mental health, and recognize the close ties between both of these domains including the ways in which physical discomfort or pain can lower the threshold for externalizing behaviors.

Recommendations

- Findings suggest that there is significant need for community outreach, education and training regarding the diagnosis of anxiety (including trauma) in youth with an ASD. Much of the needed training is underway and it is anticipated this trend will change over the next few years reflecting increased capacity in the local system. With increased recognition of trauma and anxiety related disorders, the diagnoses of disruptive disorders are often reduced.
- In addition to a focus on anxiety and trauma related disorders, design and provide additional trainings focused on differential diagnosis of bipolar disorder and psychosis, anxiety seen in people with IDD in an ongoing effort to increase the capacity to support the needs of individuals with IDD and behavioral health challenges.
- Design and provide additional trainings focused on identification of common medical comorbidities experienced by people with IDD are needed.
- Review diagnoses at intake for individuals referred over time, looking for trends showing better detection of anxiety, trauma and medical problems.
- See detailed suggestions for training topics in section below regarding *Primary Services*.

[2] Arif, A. A., & Korgaonkar, P. (2016). The association of childhood asthma with mental health and developmental comorbidities in low-income families. *Journal of Asthma*, *53*(3), 277-281

Section III: Emergency Service Trends

Table III.A: Emergency Service utilization

Variable	Children	Adults
N	92	168
Psychiatric Hospitalizations		
Prior to enrollment, N (%)	**28 (30%)**	**65 (39%)**
Mean Admissions (range)	1.9 (1-4)	2.4 (1-10)
Missing	-	2 (1%)
During START, N (%)	**5 (5%)**	**12 (7%)**
Mean (range)	1.0 (1)	1.4 (1-4)
Average length of stay (days)	25 days	9 days
Emergency Department Visits		
Prior to enrollment, N (%)	**32 (35%)**	**90 (54%)**
Mean Visits (range)	2.1 (1-17)	4.4 (1-30)
Missing	-	3 (2%)
During START, N (%)	**8 (9%)**	**23 (14%)**
Mean (range)	1.4 (1-3)	3.8 (1-16)

Figure III.A: Change in frequency of pre and post START enrollment emergency service utilization (children)

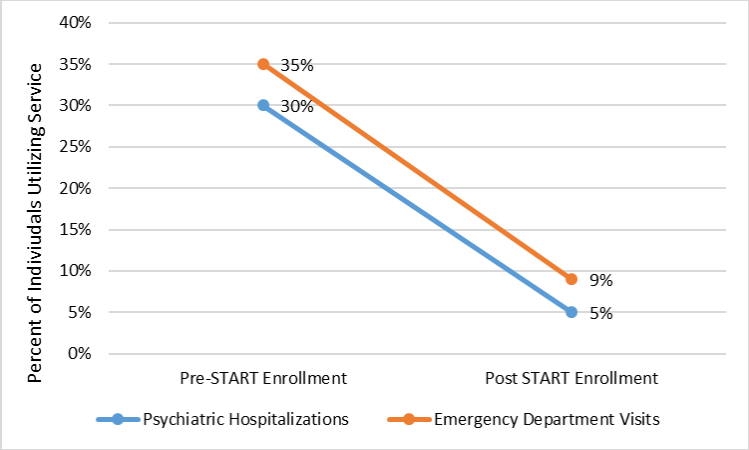
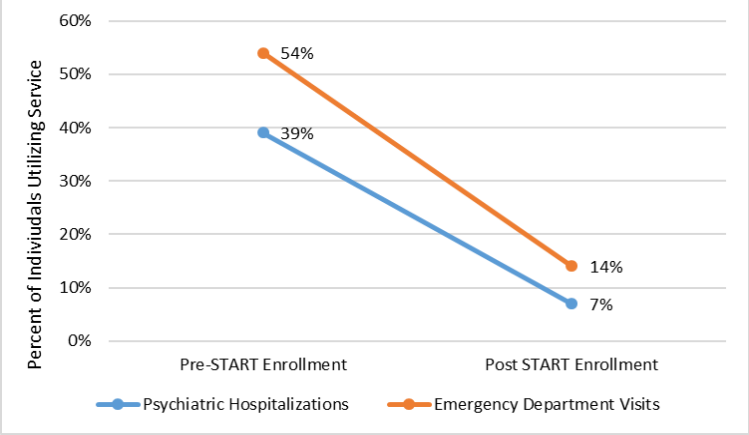


Figure III.B: Change in frequency of pre and post START enrollment emergency service utilization (adults)



Summary

- Adults and children enrolled in the Region 4 Tri-Borough program have high rates of reported psychiatric emergency service use in the year prior to intake. The rates for ED use and hospitalizations are similar to those reported for Region 4 Richmond Kings, (detailed enrollment and service trends/analysis for Richmond Kings can be found in their annual report) with the exception of adult utilization of EDs which are exceptionally high. When START crisis services are engaged, these rates fall to very low levels, and trends are promising as illustrated in graphs III.A and III.B.

- There may be some ED visits and inpatient stays of which START is not informed or engaged. Ongoing efforts continue to encourage and promote use of START crisis services when prevention has not been successful. Data here suggests that START services are very effective in reducing emergency service use.

Recommendations

- See recommendations, in the *Program Enrollment* section of this report, for addressing situations where people disengage from START for no longer requesting services.

- Coordinators should examine their caseload, detect and report any instances where a START enrollee was sent to an ED or hospitalized. Additional outreach should follow to ensure that START crisis supports are accessed when early warning signs are observed as a way to avoid Ed and hospital utilization in the future.

Section IV: START Clinical Services

Based on a tertiary care approach to crisis intervention, START service measures fall into three crisis intervention modalities:

Primary (improved system capacity): Clinical Education Teams (CETs), community education, training, and system linkage;

Secondary (specialized direct services to people at risk of needing emergency services): Intake and assessment activities, Comprehensive Service Evaluations (CSE), outreach, clinical and medical consultation, and Cross Systems Crisis Prevention and Intervention Planning (CSCPIP); planned therapeutic supports (Resource Center and Therapeutic Coaching) and

Tertiary (emergency intervention services): emergency assessments and mobile support as well as other emergency services such as hospitalizations and emergency room visits used by START recipients (includes emergency therapeutic supports).

This section looks at utilization patterns in each of these services**.** The goal of START is to support and assist the system in moving from tertiary care (emergency level of crisis intervention services) to primary intervention (able to assist when vulnerable) and secondary services (getting expert assistance without the use of emergency department utilization or psychiatric hospitalization). This is achieved by building capacity across the service system in order to prevent and assist with potential problems rather than manage them as crises later.

Primary Services

Building system capacity to support individuals in their homes and communities.

The following is a summary of the primary service activities reported by Region 4 Tri-Borough team members since program operations began. Primary START services include system linkages, education and community training. These services are part of the plan to improve the capacity of the system as a whole so that improvements are effective and sustainable over time. Over the last year, the NYSTART team has engaged the community to provide training and education around the unique needs of individuals with IDD and co-occurring behavioral health issues and continues to engage the system to become active participants in the START learning community.

Table IV.A: Community training activities

Number of Activities (N)	
Community-based training	28
Host Advisory Council Meeting	6
Provided Training (N)	
Day provider	7
Emergency services	2
Family	27
Other	34
Physician/medical personnel	11
Residential provider	24
School	19
State facilities (state hospitals, developmental centers)	3
Therapist/mental health providers	12
Transition Support/Planning-Developmental Center	1
Transition Support/Planning-Psychiatric Hospital	4
Total Community Outreach/Training Episodes (N)	178
Total Linkage/Collaboration Agreements Completed (N)	48
Total Clinical Education Teams in FY17/18 (N)	11

In addition to the above reported specific training and linkage activities, a number of more informal outreach efforts were made. These included providing community partners with information about START and issues pertaining to the population served, as well as discussions about ways to collaborate. More information about these activities can be obtained from the Region 4 Tri-Borough Program Director.

The following is a list of some of the training provided to the community as part of the primary services provided by the program since operations began.

Table IV.B Community Training – 20172018 Region 4 Tri-Borough

Date	Location	Training	Attendees
7/18/17	Mental Health Consultants Department of Ed.	Introduction to START	6
9/19/17	PS 721 M	Introduction to START	10
9/28/17	Central Office	Introduction to START	12
9/30/17	PS 130	Introduction to START	8
10/3/17	Mental Health Service corps	Introduction to START	17
11/7/17	ASD and IDD – PS 721 M	Training for Para professionals	26
11/14/17	NY Columbia Presbyterian Hospital	Introduction to START	22
11/15/17	Jacobi Grand Rounds	Persons with ID/ASD and Complex Behavioral Health Needs	25
11/16/17	Mental Health Consultants - DOE Queens	Introduction to START	12
1/3/18	District 75 Transitional Coordinators	ID and ASD	40
1/8/18	MSC Committee	Introduction to START	39
1/23/18	Community Options Inc.	Introduction to START	9
2/1/18	New Manager Training YAI	Introduction to START	22
2/7/18	Jacobi Emergency Room RNS	De-escalating techniques for people diagnosed with ID	15
2/8/18	Legal Advocates for Children	Introduction to START	12
3/1/18	Charles B Wang Community Medical Center	Introduction to START	9
3/22/18	Community Training	Introduction to START	11
4/18/18	North Central Bronx Hospital	Persons with IDD/ASD and Complex Behavioral Health Needs	22
			317 Total Attendees

Table IV.C: Clinical Education Team Meetings – Dates, Topics & Number in Attendance

Date	Training	Attendees
5/25/17	Diagnosis of Bipolar and Persons with IDD	8
8/2/17	Features of Velocardiofacial Syndrome in Persons with IDD	30
9/28/17	Assessment of Irritability and Challenging Behaviors for people diagnosed with ASD	15
10/30/17	People with IDD diagnosed with ASD and OCD	10
12/18/17	ASD and Schizophrenia	8
1/29/18	Using positive psychological techniques with people diagnosed with Fetal Alcohol Syndrome	24
2/26/18	Visual Impairments and IDD	22
3/12/18	Parenting IDD individuals in adolescent and early adulthood	17
		134 Total Attendees

Table IV.D: National Online Training

Date	Training	Attendees
9/15/17	Disabling Segregation	33
10/20/17	Trauma During Childhood	39
11/17/17	School based Mental Health Supports and Interconnected Systems Framework	17
1/19/18	Genetic Syndromes Associated with IDD	51
2/16/18	Surviving and Thriving Health and Wellness as a Game Changer	35
3/16/18	Substance Use in people with IDD	34
4/20/18	From Stability to Flourishing – Practical Strategies for Promoting Mental Wellness	23
		232 Total Attendees

National START Practice Groups

As part of the START the national START Professional Learning Community, NYSTART staff participate regularly in national study groups with other professionals. These forums are opportunities to gain knowledge and skills needed to improve system capacity. The goal of these groups is to ensure that all START teams have the latest knowledge and technical support to provide evidence-based services in all areas of service provision. These study groups include:

- Clinical Directors Study Group, facilitated by Jill Hinton, Ph.D.
- Children's Services Study Group facilitated by Karen Weigle, Ph.D.
- Resource Center Directors Study Group, facilitated by Bob Scholz, M.S., LMHC
- Medical Directors Study Group, facilitated by Karen Weigle, Ph.D. and Laurie Charlot, Ph.D.
- Team Leaders Study Group, facilitated by David O'Neal, MS, and Alyce Benson, MSW
- National Program Director forums held quarterly facilitated by Andrea Caoili, LCSW and Joan B. Beasley, Ph.D.
- The START National Training Institute chaired by Joan B. Beasley, Ph.D., Director

Summary

- The Region 4 Tri-Borough team provided a significant number of trainings this year. The program recognizes that the work with individuals, their caregivers and teams is very important but that capacity building from a primary level of intervention is also necessary in order to make an impact.
- All of the training offered was positively received. The specific training at Grand Grounds at Jacobi and North Central Bronx Hospitals were important as these reach community partners who see many individuals served in START and are well attended events. In these trainings, the Clinical, Medical and Assistant Directors presented and facilitated a discussion on persons with IDD/ASD and Complex behavioral needs. CEs were offered and over fifty health care professionals attended including psychiatrists, hospital social workers and ED Physicians.
- Clinical Education Team (CET), case based trainings, showed a pattern of increasing attendance, so that more people were reached with this very effective form of training.

Recommendations

- Despite the large number of trainings noted above, more is needed regarding differential diagnosis of bipolar disorder and psychosis, trauma related disorders and recognizing anxiety as a common clinical driver of externalizing behaviors and symptoms in the population we support. The program should plan to deliver trainings on these topics throughout the upcoming fiscal year.
- Multiple training opportunities are needed regarding common medical issues and medication side effects as factors that commonly underlie aggressive and other challenging behaviors of people with IDD.

Secondary Services

Specialized direct services to people at risk of emergency service use

Secondary services help to ensure that individuals are getting the supports they need to intervene effectively in times of stress and avoid costly and restrictive emergency services.

The following planned, secondary services are offered by all START programs and time spent on these activities is tracked in SIRS.

- *Intake/Assessment:* Work done to determine the needs of the individual and their team, and the services to be provided. Includes: Information/record gathering; intake meeting; completion of assessment tools; and START action plan development.
- *Outreach*: Any time the START Coordinator provides informal education or outreach to the system of support related to general issues or those specific to the individual. Entities to which the START Coordinator may provide outreach: families/natural supports, residential programs, day programs, schools, mental health facilities, or any entity that may seek or need additional support and education.
- *Clinical Consultation*: Consultations provided by the Clinical Director with community team members who support individuals. Recommendations are given facilitation of goal and action plan development is done by the START Coordinator.
- *Medical Consultation:* Consultation provided by the START Medical Director regarding medication and other medical issues, includes collaboration with prescribing doctor. Recommendations are given facilitation of goal and action plan development is done by the START Coordinator.
- *Cross System Crisis Planning*: Completion of the Cross Systems Crisis Intervention and Prevention Plan (CSCPIP) includes collecting and reviewing relevant information; brainstorming with the team; developing/writing the plan and distributing; reviewing and revising; and training and implementation the plan with the system of support.
- *Crisis Follow-Up*: Time spent following up after a crisis contact. This includes facilitating emergency service admissions and discharges, meetings with emergency service providers and follow-up on crisis plan recommendations.
- *Facilitation of Planned Therapeutic Supports (Resource Center, Therapeutic Coaching)*: Work/coordination related to preparing for and facilitating planned center based or in-home supports.
- *Clinical Education Team (CET)*: Preparing for and holding a CET regarding the enrolled individual. Includes reviewing and identifying relevant recommendations with Clinical Director and assisting system of support with implementing recommendations.
- *Comprehensive Service Evaluation (CSE)*: Completion of the CSE, including receiving and reviewing records; interviewing the individual and system of support; writing the CSE; and reviewing recommendations through development of an action plan.

Table IV.E shows the percent of individuals enrolled in the region who received these START services during the year. Since each individual enrolled in START is at a different stage of case activity and has unique strengths and needs, not all individuals received all planned services in the reporting period.

Table IV.E: Percent of Individuals Enrolled Receiving START Planned Services

Variable	Children	Adults
N	92	168
Utilization of Planned Services (% of Individuals)		
Outreach	88%	89%
Intake/Assessment	97%	95%
CSCPIP	68%	80%
Clinical Consultation	55%	61%
Medical Consultation	39%	51%
Therapeutic Supports	8%	13%
Crisis Follow-Up	33%	40%

START Intake, Assessment and Tools

All individuals who are enrolled in START services participate in an initial Intake/Assessment process in which the START team gathers important historical and biopsychosocial information about the individual and his/her system of support. This process informs the next step, which is the development of a START Action Plan, outlining specific services and resources that the START Program will provide. Assessment tools used during the intake They also include the Aberrant Behavior Checklist (ABC), Recent Stressors Questionnaire (RSQ), and START Action Plan are re-administered or updated on a regular basis as long as the individual is enrolled and actively receiving START services.

The Aberrant Behavior Checklist (ABC), developed by Aman and Singh, is completed for all enrolled individuals at the time of intake and every 6 months thereafter until the enrolled individual is stabilized. The ABC is frequently used as a measure of treatment outcomes in studies including people with IDD.

The Recent Stressors Questionnaire (RSQ), developed by Laurie Charlot, LCSW, Ph.D. is also completed at time of intake and as part of the emergency assessment process. The RSQ is a valuable assessment tool and assists the coordinator with gathering important biopsychosocial information about the individual and their crisis experience.

Table IV.F shows the percentage of individuals active in the reporting period that have completed and up-to-date START assessments and tools.

Table IV.F: Provision of Planned START Clinical (Coordination) Services

START Tools	Completed	Up-to-date
START Action Plan	93%	85%
Aberrant Behavior Checklist (ABC)	95%	89%
Recent Stressors Questionnaire (RSQ)	96%	94%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIP)	91%	92%
Comprehensive Service Evaluations (CSE)	5%	N/A

Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item informant report psychopathology rating tool designed specifically for use with individuals with IDD. (Aman, Burrow, & Wolford, 1997).

The ABC has been reported in the literature as an *outcome measure*, having demonstrated sensitivity to detecting changes in psychopathology ratings over time in response to a specific intervention. The ABC is used here to determine if use of START services is associated with reduced psychopathology ratings over a 6 month or greater period of time. When using the ABC, the authors suggest use of the subscales, and not a total scale score. Subscales were identified via a factor analytic process, and

three of these have been reported as sensitive to treatment effects, including the *Irritability*, *Hyperactivity* and *Lethargy* scales; so these are reported below for active enrolled Region 4 Tri-Borough cases.

The ABC is administered to START service recipients at intake and again at 6-month intervals. For this analysis, only individuals enrolled in START services for at least 6 months with at least two ABC scores were included (N=171). The average time between the two administrations used in this analysis was 16 months.

Table IV.G: ABC Analysis

		Mean			
Region 4 Tri-Borough (N=94)	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one-tail**
Hyperactivity/Noncompliance	55%	24.07	20.63	2.87	<0.00
Irritability/Agitation	56%	23.98	20.34	3.00	<0.00
Lethargy/Social Withdrawal	41%	13.95	13.56	.38	NS

Alpha=0.05

Summary

- Individuals enrolled in the Region 4 Tri-Borough program have been receiving most of the required secondary level services and core assessments, meeting standards with some exceptions. The percentage of individuals who received CSCPIP planning services was low. Based on some of the data reported regarding individuals with repeated crisis events, the number of CSEs completed is also low. The goal for completion of CSEs is 15-20% of the current active caseload. The program is not yet meeting standards in this area.
- The ABC data shows positive trends demonstrating significant improvement over time when receiving START services in the major two subscales, Irritability and Hyperactivity, which are those most represented in major intervention studies as key outcome measures. The reduction in the Lethargy subscale was non-significant.
- Though reduced ABC scores can be a very useful outcome measure, other factors may also be important in determining the effectiveness of interventions, including helping people remain with their natural supports (also a positive outcome measure). Other data suggest that individuals served in START demonstrate improved functioning based on the large reduction in ED visits and psychiatric inpatient stays noted above. Collectively, these outcome measures suggest the START model is helping significant numbers of enrollees.

Recommendations

- The Region 4 Tri-Borough leadership team should develop a plan of action to:
    - Increase time spent on CSCPIP development and updates. Cases not making progress need routine outreach and adjustments to CSCPIPs, and not just annual updates.
    - Increase completion of CSEs to a rate of 15-20% of open cases, focusing on individuals who are not demonstrating a steady course of improvement and for whom there are important unresolved questions regarding clinical and systemic challenges that may be preventing the person from achieving a state of mental wellness.

Tertiary Services

Emergency interventions provided during a crisis

START tertiary services include the time spent responding to crises, facilitating necessary emergency supports, and transitioning individuals to facilities providing lower levels of care. *A Crisis Contact is defined as:* An emergency call received by the START team that requires immediate triage and response, likely resulting in an in-person emergency assessment. Assessment can be conducted in a number of settings including: family home, residential setting, day program, hospital emergency department, etc. In some cases, the on-call coordinator may provide consultation to family or caregivers over the phone, or may speak with the individual to help restore calm, and avert the need for higher levels of intervention.

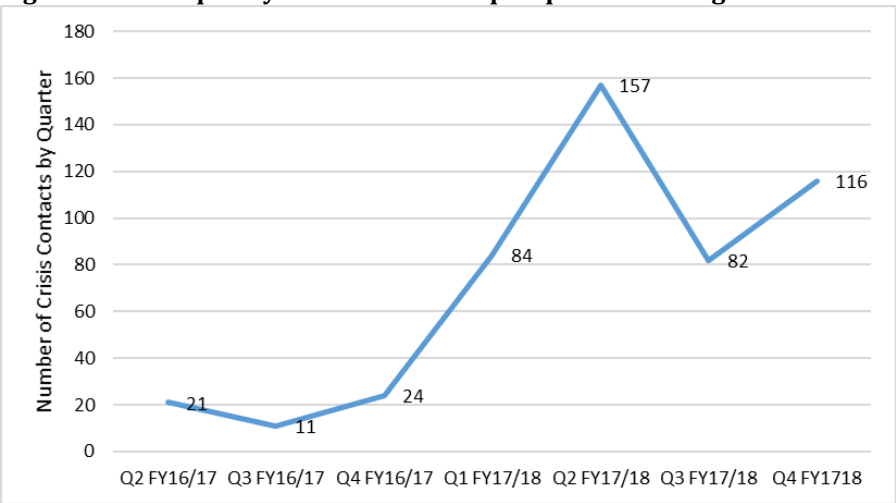
Crisis Contacts

Region 4 Tri-Borough coordinators provide 24-hour crisis response for individuals enrolled in their program. Data here reflect trends for crisis calls received by quarter since program inception through the end of FY 2017/2018 (March 31, 2018). During the period of this report, Region 4 Tri-Borough responded to 379 crisis calls from 82 different individuals (32% of population).

Table IV.H: FY17/18 Crisis Contacts

Variable	Children	Adults
Crisis Contacts		
Number of Individuals with a crisis contact	24	58
Number of individuals with documented crisis follow-up	28	67
Number of Crisis Contacts	86	293
Range of Contacts	(1-21)	(1-27)
Type of Intervention		
In-Person	39 (45%)	185 (63%)
Phone Consultation	47 (55%)	108 (37%)
Missing	-	-
Average Length of In-Person Intervention	3.1 hours	2.8 hours
Crisis Disposition		
Maintain Setting	77 (90%)	228 (78%)
Psychiatric Hospital Admission	4 (5%)	12 (4%)
Emergency Department	3 (3%)	32 (11%)
Medical Hospital Admission	-	-
START Therapeutic Services	-	-
Crisis Stabilization	1 (1%)	7 (2%)
Other (Incarcerated, Referral to services, "Other")	-	7 (2%)
Unreported	1 (1%)	7(2%)

Figure IV.A: Frequency of crisis contacts per quarter for Region 4 Tri-Borough enrollees.



Summary

- In a large number of the adult cases, on-call coordinators responded in person when a crisis was reported. However, this was not the case with children enrollees for whom in person evaluation rates were lower. The coordinators responding in person are able to conduct a direct assessment, providing supports and recommendation that contributed to the prevention of hospital admissions. It is expected that about 75% of crisis calls should be addressed with an in-person assessment.
- Positive trends are seen in regard to the outcomes of individuals receiving crisis evaluations as most are able to remain "in setting," with few needing more restrictive interventions.
- Data here show that some individuals had as many as 20+ crisis contacts. In these instances, extra outreach, and application of all START components should be brought to bear to resolve the ongoing challenges the person is experiencing.
- Availability of the program's newly opened Resource Center (May 2018), and the added component of Therapeutic Coaching (services that have been in developmental stages this FY) will likely be helpful in even further reducing crisis events adding key services to the existing ones available through START.

Recommendations

- Review repeat crisis contact cases and ensure these are not 'warm line" contacts. If so, design alternative means that the individual can access the supports needed. Review all cases with > 10 crisis contacts and ensure that a CSE is completed, outreach is adequate and reflected in the START Plan. Also, these individuals may now be screened for potential need for emergency therapeutic supports.
  For any people with 10 or more crisis calls, the case should be reviewed by the Clinical Director. The Clinical director should then work with the coordinator to take the steps outlined below. The following should be considered:
  - If calling the crisis line when not in crisis -schedule phone calls to meet the person's need for contact in a preventive manner
  - Update the CSCPIP with close involvement of the person's system of care.
  - Check the START plan and ensure this is in alignment with the high need profile of the cases reviewed.
  - Present the case to the medical director.
  - Complete a CSE.
  - Organize a systems meeting and review.
  - If appropriate, schedule a CET.
  - Develop a detailed action plan to reduce crisis events based on above and in conjunction with the person's system of care.

- In situations where the agency working with a person having many crisis contacts is reluctant or feels they are unable to follow START recommendations, continue with systemic work as a key intervention to help support individuals in these situations. Continue to work closely with OPWDD and other stakeholders to develop collaborative remedies, and seek support from the Center for START Services.

Section V: START Therapeutic Services

*At the time of this report the resource center for Region 4 Tri-Borough was just opening.

START In-Home Therapeutic Coaching

NYSTART Therapeutic Coaching services are designed to be a short term, therapeutic services provided to an individual in their current setting. The need for this service is determined by the Start Coordinator in collaboration with the Clinical Director, Therapeutic Coaching Team Leader, individual and their circle of support. Person centered, positive psychology based approaches are used to address identified goals that help enhance an individual's social skills, coping strategies, and other related skills while enhancing the system's ability to support the individual through psycho-education and training. Therapeutic Coaching supports can be provided within a variety of settings including family homes, an individual's own home, group homes, day support programs, CPEPs, and residential treatment facilities. The purpose is to provide the individual and system with enhanced understanding, skills and tools to successfully address stressful situations. Other outcomes include the maintenance of the individual's current residence and/or services and to assist the individual and team in linking to services.

Table V.A: In-Home Supports

Variable	Children	Adults
In-Home Therapeutic Coaching Individuals Served	3	5
Average number of hours (range)	31 (13-61)	21 (1-63)
Total hours provided	92	106
Percent Emergency Hours	15%	6%

Summary

- In-Home Therapeutic Coaching is very new and the program continues to hire and train staff for this service. It is expected that the service will be an important contribution to assisting individuals in need of short term supports. This service provides a platform for observation, data tracking, informed case formulation and teaching positive skills to individuals and caregivers.

Recommendations

- Region 4 Tri-Borough team will be working to fully develop In-Home Therapeutic Coaching and Resource Center services. The team will collaborate with the Center for START Services to refine practices and provide ongoing training to staff.

- Key goals for coaching should be to ensure that each of the three recently hired coaches has a full caseload with goal of serving 50 families by the end of FY 2018/2019. Goals for the Resource Center will be to maintain a high rate of bed occupancy with a minimum of 85-90% for both planned and emergency admissions.

Conclusions and Recommendations for Fiscal Year 2018/2019

Conclusions

The NYSTART Region 4 Tri-Borough provided services to 260 individuals since its inception in September 2016 including a large cohort of children (n=92). The majority of children carried an ASD diagnosis, and all of the youth and half of the adults reside with their families. A very high level of planned clinical services provided by the Region 4 Tri-Borough program meet national START fidelity standards, with a few exceptions. Cross Systems Crisis Intervention and Prevention Plan and Comprehensive Service Evaluation completion is lower than expected and it is recommended that this be addressed in the first quarter of FY 2018/2019. Data for both the ABC (measure of extent of psychopathology) and emergency service use when START responds to a crisis call, demonstrate a major positive impact of the START services provided. At the conclusion of FY 2017/2018, the Region 4 Tri-Borough team launched the last two key components of the START model, Therapeutic Coaching Support Service and Resource Center services.

The Region 4 Tri-Borough team was able to provide numerous trainings to a large number of stakeholders from diverse backgrounds, including Grand Grounds at Jacobi and North Central Bronx Hospitals. These primary level activities serve to reach and benefit more individuals than other services provided. Despite all of these efforts, areas of additional education are needed. Most individuals served by the Region 4 Tri-Borough program had a psychiatric diagnosis reported at intake, and many individuals had more than one, which is similar to other START programs. However, very low rates of diagnosed anxiety disorders, yet high rates of diagnoses of ASD in children clearly indicates there is more work to be done. The rates of over 50% of the adults served having either a bipolar disorder or a psychotic disorder further points to educational needs of the diagnosticians working in the area. Educating the system of support about the occurrence of anxiety driven aggression, medical challenges and trauma related concerns are needed since diagnoses at intake show a pattern consistent with a lack of evidence informed mental health assessment has been common in the community system.

High rates of asthma reported for the children is consistent with national data trends but there were too few individuals with reported neurological and GI challenges, which is very consistently reported in other programs and other studies of people with IDD.

Areas for focus in FY 2018/2019 are listed below. The data suggesting that people who could benefit from START services will at times disengage from them is concerning and recommendations provided aim to mitigate these occurrences.

Recommendations for Fiscal Year 2018/ 2019

Program Enrollment

- Closely study all occurrences of individuals enrolled in START who are made inactive due to disengaging and develop processes and new approaches to retain individuals in the program who are seen as potentially benefitting from the services and inform them of the supports available.
- Implement steps and review data quarterly to ensure rates of inactivation of cases due to "no longer requesting services" is <10% by the 3rd quarter of FY 2018/2019.
- Continue to conduct outreach, consultation and training to increase the skills of clinicians and others in the local system of care in regard to the multiple influences on behavioral health challenges.

Characteristics of Persons Served

- Demographics
    - Participate in national training opportunities offered regarding cultural competence as applied to work with individuals with IDD and then develop and deliver training to community partners to address this topic.
- Mental Health and Chronic Health Conditions
    - Findings suggest that there is significant need for community outreach, education and training regarding the diagnosis of anxiety (including trauma) in youth with an ASD. Much of the needed training is underway and it is

anticipated this trend will change over the next few years reflecting increased capacity in the local system. With increased recognition of trauma and anxiety related disorders, the diagnoses of disruptive disorders are often reduced.

- In addition to a focus on anxiety and trauma related disorders, design and provide additional trainings focused on differential diagnosis of bipolar disorder and psychosis, anxiety seen in people with IDD in an ongoing effort to increase the capacity to support the needs of individuals with IDD and behavioral health challenges.
- Design and provide additional trainings focused on identification of common medical comorbidities experienced by people with IDD are needed.
- Review diagnoses at intake for individuals referred over time, looking for trends showing better detection of anxiety, trauma and medical problems.
- See detailed suggestions for training topics in section below regarding *Primary Services*.

Emergency Service Trends

- See recommendations, in the *Program Enrollment* section of this report, for addressing situations where people disengage from START for no longer requesting services.
- Coordinators will be asked to examine their caseload, detect and report weekly any instances where a START enrollee was sent to an ED or hospitalized and the START crisis line was not used. Additional outreach will then be conducted to ensure this is not happening (as much as possible).

START Clinical Services

- Primary Services
  - Despite the large number of trainings noted above, more is needed regarding differential diagnosis of bipolar disorder and psychosis, trauma related disorders and recognizing anxiety as a common clinical driver of externalizing behaviors and symptoms in the population we support. The program should plan to deliver trainings on these topics throughout the upcoming fiscal year.
  - Multiple training opportunities are needed regarding common medical issues and medication side effects as factors that commonly underlie aggressive and other challenging behaviors of people with IDD.
- Secondary Services
  - The Region 4 Tri-Borough leadership team should develop a plan of action to:
    - Increase time spent on CSPIP development and modifications. Cases not making progress need routine outreach and adjustments o CSCPIP plans, and not just annual updates.
    - Increase completion of CSEs to a rate of 15-20% of open cases, focusing on individuals who are not demonstrating a steady course of improvement and for whom there are important unresolved questions regarding clinical and systemic challenges that may be preventing the person from achieving a state of mental wellness.
- Tertiary Services
  - Review repeat crisis contact cases and ensure these are not 'warm line" contacts. If so, design alternative means that the individual can access the supports needed. Review all cases with > 10 crisis contacts and ensure that a CSE is completed, outreach is adequate and reflected in the START Plan. Also, these individuals may now be screened for potential need for emergency therapeutic supports.

    For any people with 10 or more crisis calls, the case should be reviewed by the Clinical Director. The Clinical director should then work with the coordinator to take the steps outlined below. The following should be considered:
    - If calling the crisis line when not in crisis -schedule phone calls to meet the person's need for contact in a preventive manner
    - Update the CSCPIP with close involvement of the person' system of care

- Check the START plan and ensure this is in alignment with the high need profile of the cases reviewed
- Present the case to the medical director
- Complete a CSE
- Organize a systems meeting and review
- If appropriate, schedule a CET
- Develop a detailed action plan to reduce crisis events based on above and in conjunction with the person's system of care

- In situations where the agency working with a person having many crisis contacts is reluctant or feels they are unable to follow START recommendations, continue with systemic work as a key intervention to help support individuals in these situations. Continue to work closely with OPWDD and other stakeholders to develop collaborative remedies, and seek support from the Center for START Services.

START Therapeutic Services

- Region 4 Tri-Borough team will be working to fully develop In-Home Therapeutic Coaching and Resource Center services. The team will collaborate with the Center for START Services to refine practices and provide ongoing training to staff.

- Key goals for coaching should be to ensure that each of the three recently hired coaches has a full caseload with goal of serving 50 families by the end of FY 2018/2019. Goals for the Resource Center will be to maintain a high rate of bed occupancy with a minimum of 85-90% for both planned and emergency admissions.