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 Richmond Kings

## 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

NYSTART Region 4 Richmond Kings
463 7th Avenue, 17th Floor
New York, NY 10018
646.565.5890

# Table of Contents



*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.*


*The Center for START Services, UNH Institute on Disability/UCED*
*56 Old Suncook Road, Suite 2, Concord, NH 03301 |* start.iod@unh.edu */ (603) 228-2085*
www.centerforstartservices.org

# Introduction

This report offers a comprehensive summary of services provided by the NYSTART Region 4 Richmond Kings team for FY 2017/2018. This team covers the New York City boroughs of Brooklyn and Staten Island. 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:

- FY 2017/2018 Enrollment Trends
- Characteristics of Persons Served (demographics and clinical trends)
- Emergency Service Trends
- START Clinical Team Services
- START Therapeutic Supports

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

Contributors to this report and the information in it are:

Ann Klein, MA, SIRS Manager; Center for START Services

Laurie Charlot, Ph.D., National Consultant, Center for START Services

Andrea Caoili, LCSW, Director of Quality Assurance; Center for START Services

Jill Hinton, Ph.D., Clinical Director/NYSTART Project Facilitator, Center for START Services

Sharon Cyrus-Savary, Director, NYSTART Richmond Kings

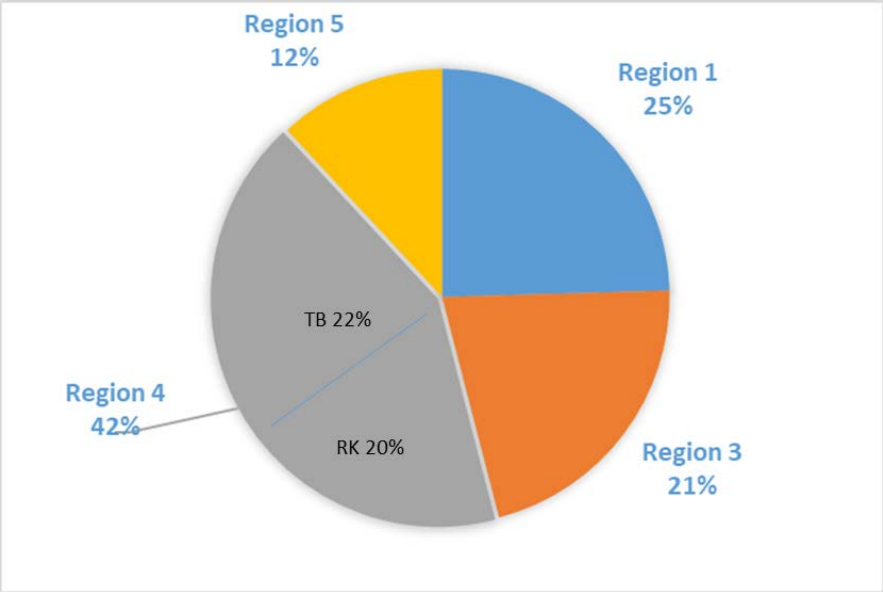
Angie Francis, B.S., NYSTART Statewide Coordinator, NYS Office for People with Developmental Disabilities

NYSTART Richmond Kings Program

# Program Background

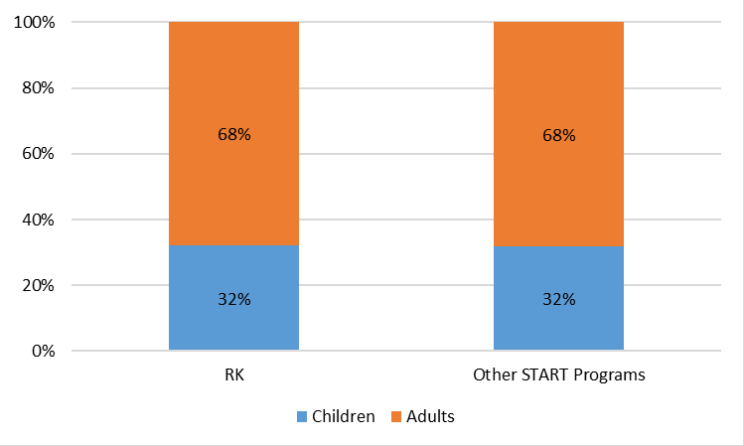
NYSTART Region 4 Richmond Kings (RK) team began operations in September 2016 and has served a total of 200 individuals. It currently represents about 20% of the active NYSTART population (see figure 1). All NYSTART programs are lifespan (serving individuals aged 6 and older), and currently children under the age of 18 make up 32% of the Richmond Kings caseload. This is identical to the Tri-Borough (TB) team, which also operates in New York City in the boroughs of Bronx, Manhattan and Queens, and is consistent with START programs nationally (see figure 2).

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




* Region 5 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 RK and Other START Programs**



The figure below shows the number of individuals newly enrolled in Region 4 Richmond Kings each quarter since program operations began.

**Figure 3: Number of Individuals Enrolled in Richmond-Kings by Quarter (n=200)**

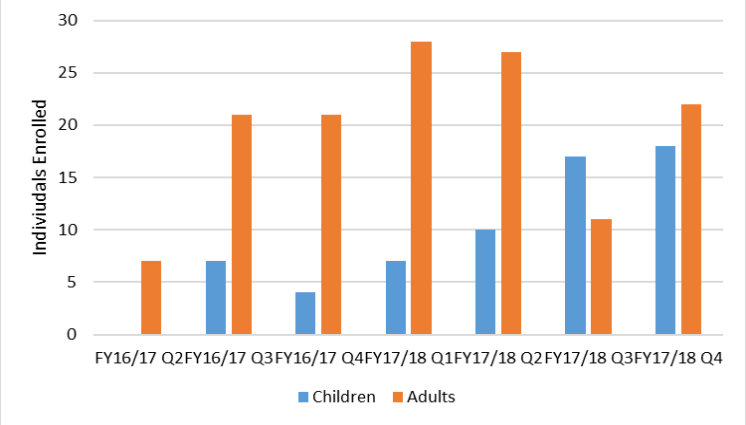
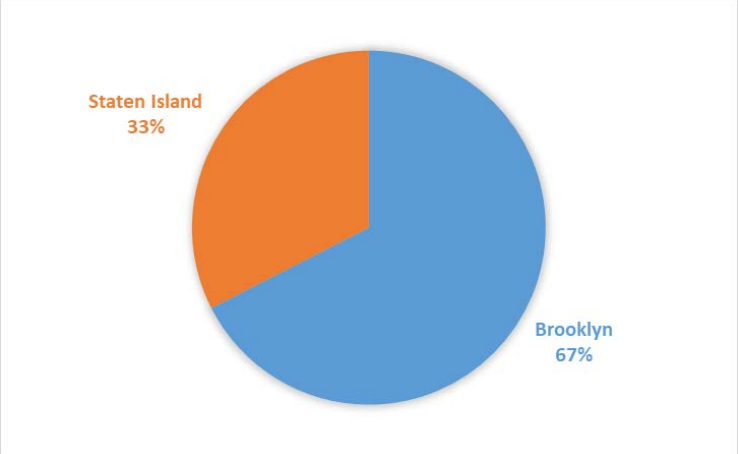



**Figure 4: Individuals Enrolled in Richmond-Kings by Borough (n=200)***




As expected, Brooklyn serves a greater proportion of the individuals enrolled in Region 4 Richmond Kings. However, the rate of enrollments in Staten island has been higher than expected given the population of that borough. All Region 4 Richmond Kings coordinators are serving individuals in Staten Island and the program is considering designating additional staff if the referral rates continue to stay consistent.

# Findings

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

All descriptions of enrollment trends, characteristics of persons served, emergency service trends, and service outcomes of those served by Region 4 Richmond Kings are based on data entered into the START Information Reporting System (SIRS) by program staff. When noteworthy, elements will be compared to other NYSTART programs or to national trends from other START programs outside of NY State (n=374 children and n=790 adults).

# Section I: FY 2017/2018 Program Enrollment

Data below reflect all individuals served by Region 4 Richmond Kings during this report period.

**Table I.A: Census Summary**

| Variable | Children | Adults |
|---|---|---|
| *Total Served during reporting period N(%)* | 63 (32%) | 137 (68%) |
| *Individuals inactivated* | 7 | 17 |
| Stable functioning | 2 (29%) | 12 (70%) |
| Moved out of START region | 1 (14%) | 2 (12%) |
| No longer requesting services | 3 (43%) | 2 (12%) |
| Inappropriate for services | - | 1 (6%) |
| No contact | - | - |
| Long term placement | 1 (14%) | - |
| Deceased | - | - |
| Unreported | - | - |
| *Active Caseload at the end of reporting period* | 56 (32%) | 120 (68%) |

**Table I.B: Sources of Referral**

| Variable | Children | Adults |
|---|---|---|
| *N* | 63 | 137 |
| *Referral Source* (%) | | |
| Case Manager | 60% | 53% |
| Emergency Department/mobile crisis | 16% | 5% |
| Family Member | 11% | 9% |
| Residential/Day Provider | 3% | 22% |
| Hospital/ID Center | 2% | 4% |
| Mental Health Practitioner | 3% | 4% |
| Other (Transfer case, Behavior Analyst, School) | 5% | 3% |
| Missing | - | - |

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

| Variable | Children | Adults |
|---|---|---|
| N | 63 | 137 |
| *Most Common Reasons for Enrollment* (%) | | |
| Aggression | 92% | 88% |
| Family Needs Assistance | 90% | 46% |
| Risk of losing placement | 2% | 4% |
| Decreased Daily Functioning | 13% | 20% |
| Dx and Treatment Planning | 24% | 14% |
| Mental Health Symptoms | 48% | 68% |
| Leaving Unexpectedly | 29% | 31% |
| Suicidality | 10% | 7% |
| Self-Injurious Behavior | 25% | 25% |
| Sexualized Behavior | 13% | 12% |
| Transition from Hospital | 3% | 8% |

## Summary

- A total of 200 individuals have been served during the reporting period, and there are 176 open cases. The Region 4 Richmond Kings team has 8 coordination positions filled and 7 vacancies and is working to improve recruitment and retention. The team has been working on professional development for coordinators and the new coaches, and coordinators are participating in Certification Training Groups facilitated by the Center for START Services.
- Only a small number of individuals have been made inactive since the inception of the Region 4 Richmond Kings program, which demonstrates that when referrals are received, they are likely to be appropriate and enrolled in services. Fourteen (14) individuals were inactivated due to stability and smaller number of individuals (n =5) were inactivated due to "no longer requesting services." Teams routinely explore why any given person or system disengages and dedicate efforts to keep individuals engaged long enough to receive benefit of the services available through START.
- Like most START programs, the majority of individuals are referred from case managers. Previous research has shown that families in great need often do not engage the system of care until there are very serious, emergent situations, and even then, not consistently. This highlights the importance of START linkages with the local system so that families who may benefit from services are referred. The 22% figure for referral source of residential and day providers for adult enrollees is a little higher than typically found in START programs and may suggest that linkage with local service providers was strengthened this year.
- The reasons for referral to Richmond Kings also mirrors that of many other START programs with the vast majority referred with concerns related to externalizing behavior challenges. However, awareness among referral sources that mental health symptoms cause distress is also reflected in the documented referral concerns. START education and training to the community often focuses on increasing the understanding of how psychiatric syndromes present in people with IDD and how symptoms may actually fuel externalizing problems that more frequently bring individuals to clinical attention.

## Recommendations

- Continue efforts to fill coordinator vacancies, which will allow expansion of the program with the goal being to reach full capacity (to serve as many individuals in need as possible). Total open cases should include about 20-25 cases per coordinator.
- Work with agency administration and National Center for START Services staff to identify key characteristics for qualified staff. A plan should be developed to actively recruit additional staff as current vacancies undermines the program's ability to grow and serve as an important partner in the emergency safety net for individuals with IDD and behavioral health needs.
- Expand recruitment efforts by reaching out to schools graduating individuals with master's degrees in related fields and increasing advertising. Work closely with the Center for START Services to develop additional strategies to fill positions and stabilize the team's composition.

# 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 Richmond Kings (N=200) since program inception, September 2016. When relevant, the NYSTART Region 4 Richmond Kings population is compared to other lifespan programs.

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

| Variable | Children | Adults |
|---|---|---|
| N | 63 | 137 |
| *Mean Age* (Range) | 14 (6-17) | 31 (18-66) |
| *Gender* (% male) | 68% | 69% |
| *Race* | | |
| White/Caucasian | 37% | 45% |
| African American | 32% | 39% |
| Asian | 11% | 4% |
| Hispanic/Latino | 10% | 7% |
| Other (includes Arab, Pakistani, Egyptian and unspecified) | 8% | 3% |
| Unknown/Missing | 2% | 1% |
| *Ethnicity (% Hispanic)* | 29% | 18% |
| *Level of Intellectual Disability* (%) | | |
| No ID/Borderline | 6% | 1% |
| Mild | 35% | 45% |
| Moderate | 43% | 44% |
| Severe-Profound | 8% | 8% |
| None Noted | 6% | 2% |
| Missing | 2% | - |
| *Living Situation* (%) | | |
| Family | 97% | 55% |
| Group Home and Community ICF/DD | - | 32% |
| Independent/Supervised | - | 9% |
| Psych. Hospital/IDD Center | 2% | 2% |
| Other (Jail, Homeless, "Other") | 2% | 2% |
| Missing | - | - |

## Summary

- In terms of the make-up of the group of individuals served in the Region 4 Richmond Kings program, many factors track closely with national norms. For example, START programs tend to disproportionately serve more individuals with greater cognitive challenges than is reflective of the general population of people with an IDD. While a general population survey would find that most people with IDD have a borderline or mild cognitive disability, many people served in START have moderate or greater challenges.
- A few data points stand out for Region 4 Richmond Kings when compared to other START programs, including greater racial and cultural diversity (a characteristic of urban programs). START is committed to increasing the cultural competence of all of 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 enrollment in START services.[1]

## Recommendations

- The Region 4 Richmond Kings team should continue to work on enhancing opportunities for education and training in order to increase cultural and linguistic competency in the coming fiscal year.

[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 | 63 | 137 |
| *Mental Health Conditions* (%) | | |
| At least 1 diagnosis | 97% | 99% |
| Mean Diagnoses (range) | 2.0 (1-7) | 2.2 (1-7) |
| *Most Common MH Conditions* (%) | | |
| Anxiety Disorders | 16% | 19% |
| ADHD | 46% | 18% |
| ASD | 79% | 41% |
| Bipolar Disorders | 3% | 24% |
| Depressive Disorders | 8% | 14% |
| Disruptive Disorders | 31% | 40% |
| OCD | 7% | 9% |
| Personality Disorders | - | 7% |
| Schizophrenia Spectrum Disorders | 3% | 28% |
| Trauma/Stressor Disorders | 5% | 7% |

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

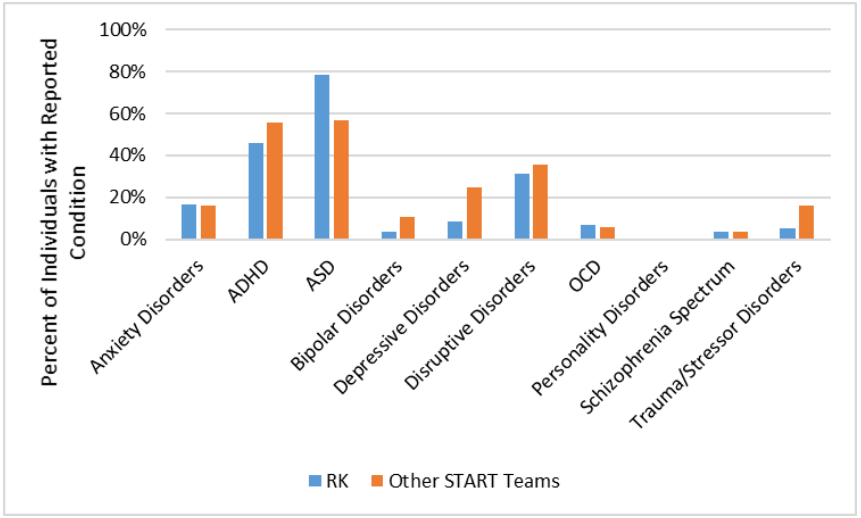



**Figure II.B: Frequency of most common mental health conditions for enrolled adults (trends across START)**

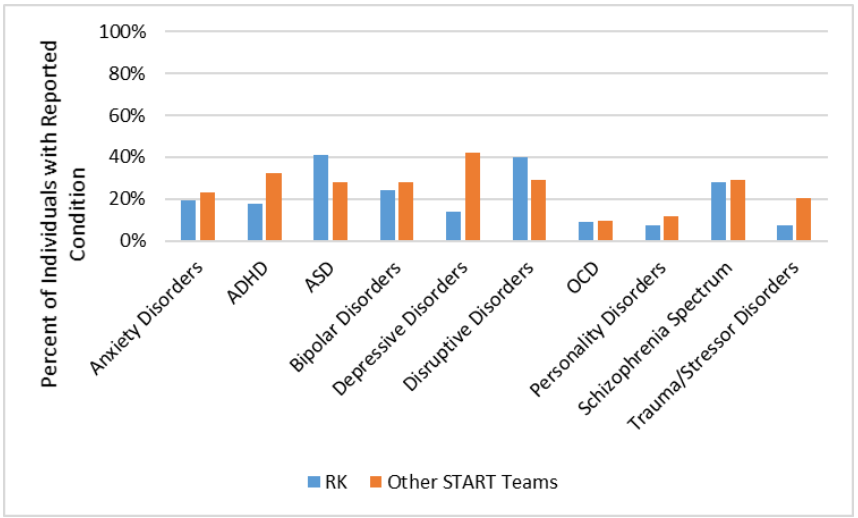


**Table II.C: Chronic medical conditions**

| Variable | Children | Adults |
|---|---|---|
| N | 63 | 137 |
| *Medical Diagnosis* (%) | | |
| At least 1 diagnosis | 60% | 77% |
| Mean Diagnoses | 1.7 (1-5) | 2.1 (1-7) |
| *Most Common Medical Conditions* (%) | | |
| Cardiovascular | 5% | 25% |
| Endocrine | 8% | 22% |
| Gastro/Intestinal | 24% | 31% |
| Genitourinary | 8% | 1% |
| Immunology/Allergy | 13% | 12% |
| Musculoskeletal | 11% | 2% |
| Neurologic | 24% | 40% |
| Obesity | 8% | 18% |
| Pulmonary disorders | 39% | 5% |
| Sleep Disorder | 3% | 8% |

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

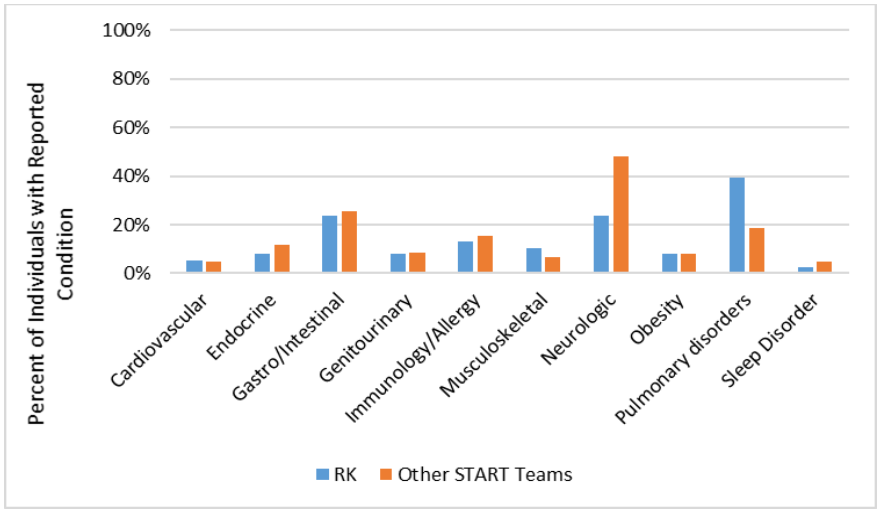
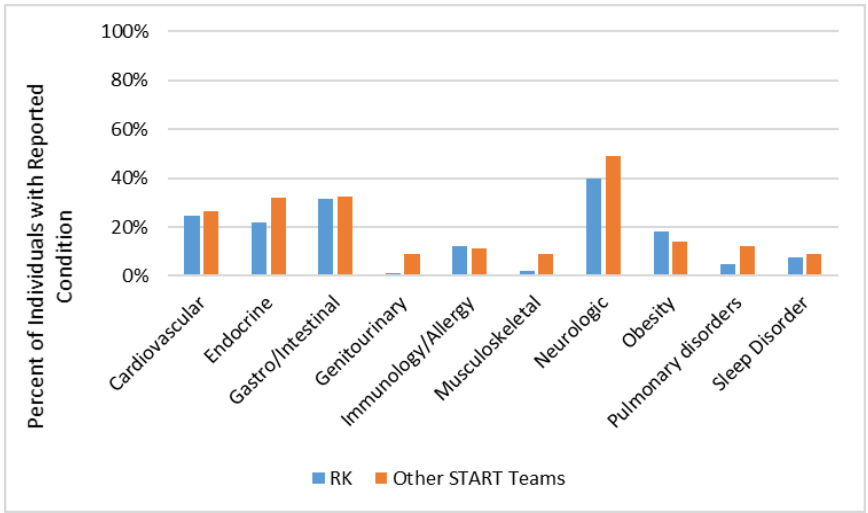



**Figure II.D: Frequency of most common medical conditions for enrolled adults (trends across START)**



## Summary

- The nature of psychiatric diagnoses at enrollment are, a reflection of the system's understanding of co-occurring mental health challenges and IDD. For example, it is known that anxiety disorders are very common among youth, especially those with an ASD. Anxiety symptoms likely act as setting events that in turn, increase the occurrence of challenging behaviors such as aggression. The high incidence of 'disruptive disorders' may indicate anxiety disorders are being missed.
- Unfortunately, trauma is very common for people with IDD and it is suspected that PTSD and trauma related challenges are under reported in this population in general. Low rates of anxiety and trauma related disorders reported at enrollment, along with higher rates of the diagnosis of bipolar disorder and psychotic disorders is common where the system of care is just beginning to receive training in special issues in the differential diagnosis of psychiatric syndromes in this population.
- Regardless of age, individuals with IDD suffer from more comorbid health conditions than individuals with neurotypical developmental profile and healthcare disparities continue to be a concern for the population. Further, individuals with IDD may engage in challenging behaviors because of feeling ill, experiencing discomfort or distress caused by an undetected medical condition. START teams receive ongoing training about these concerns, and work with Medical Directors and other partners to increase awareness of the role medical conditions play in the quality of life of people with IDD.
- Data presented suggest a slightly higher than expected percentage of adults had a reported neurological condition at intake (40%) though reports of 30-35% are not uncommon in clinically referred samples.
- Children served in Region 4 Richmond Kings have double the rate of asthma as that reported for youth in less urban START programs. Childhood asthma and mental health concerns have been linked in a number of investigations.[2]
- Both GI and neurological syndromes and associated challenges are common and occur at high rates among people with IDD and these trends are seen in this data. START continues to work to understand healthcare disparities between the general population and people with IDD so common in many areas around the world, as well as within the population we serve in the US, to inform practice improvements.

## Recommendations

- Continue and expand the scope of trainings for community partners on special issues in diagnosing psychiatric disorders in individuals with IDD.
- Design specific trainings to teach community partners about the most common medical conditions and medication side effects that may provoke or worsen behavioral and emotional symptoms.

[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 | 63 | 137 |
| *Psychiatric Hospitalization* | | |
| **Prior to enrollment**, N (%) | **21 (33%)** | **60 (44%)** |
| Mean Admissions (range) | 1.4 (1-3) | 2.0 (1-20) |
| Missing | - | - |
| **During START, N (%)** | **3 (5%)** | **12 (9%)** |
| Mean (range) | 2.0 (1-4) | 1.9 (1-5) |
| Average length of stay (days) | 12 days | 10 days |
| *Emergency Department Visits* | | |
| **Prior to enrollment, N (%)** | **27 (43%)** | **62 (45%)** |
| Mean Visits (range) | 2.9 (1-14) | 4.8 (1-30) |
| Missing | - | - |
| **During START, N (%)** | **6 (10%)** | **32 (23%)** |
| Mean (range) | 2.2 (1-7) | 2.0* (1-43) |

*There is one adult with 43 ED visits. The range omitting these outliers is 1-11. The calculated mean excludes outlier.

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

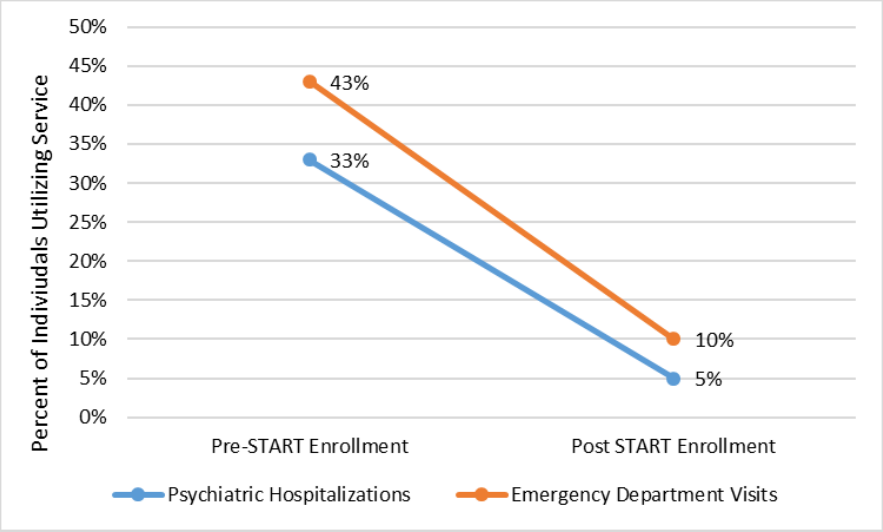
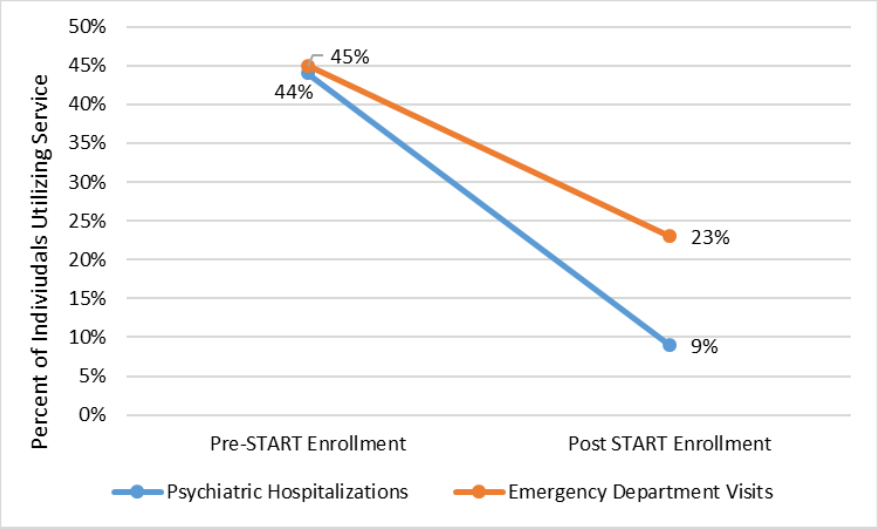


**Figure III.B: Change in frequency of pre and post START enrollment emergency service utilization (adults)**




## Summary

- Region 4 Richmond Kings was able to make a significant impact on the rate of emergency service use for individuals enrolled. START teams work diligently to educate caregivers and individuals to encourage them to collaborate on developing crisis prevention and intervention strategies and to call START for help.

- There were some individuals who had multiple ED visits and/or inpatient psychiatric stays, indicating more work will be needed to ensure that adequate outreach, engagement and use of the full array of START services are being employed in these cases. The Region 4 Richmond Kings Therapeutic Supports including In-Home Coaching and Resource Center based services, which are still very new and will be helpful for these individuals going forward.

## Recommendations

- Coordinators should examine their caseload and report during triage if there are any individuals who have had an emergency service. A plan should be developed to increase engagement of START as a way to improve rapport and working relationships with caregivers of individuals enrolled in services.

- Going forward, the following steps should be taken to address this area if not already done for any case with 10 or more crisis calls:
    - Initial review by Clinical Director who should work with coordinator.
    - 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.

# 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 Richmond Kings 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 | 37 |
| Host Advisory Council Meeting | 1 |
| *Provided Training (N)* | |
| Day provider | 6 |
| Emergency services | 1 |
| Family | 30 |
| Other | 5 |
| Physician/medical personnel | 1 |
| Residential provider | 14 |
| School | 9 |
| State facilities (state hospitals, developmental centers) | 1 |
| Therapist/mental health providers | 2 |
| Transition Support/Planning-Developmental Center | 2 |
| Transition Support/Planning-Psychiatric Hospital | 4 |
| *Total Community Outreach/Training Episodes (N)* | 113 |
| *Total Linkage/Collaboration Agreements Completed (N)* | 93 |
| *Total Clinical Education Teams in FY17/18 (N)* | 14 |

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 local START Program Director.

The following list includes the training provided in the community as part of the primary services provided by the program since operations began. Due to some diagnostic trends and education needs identified in the system, some of these topics have been revisited and offered multiple times for different audiences throughout the region.

ADHD & Bipolar
Anxiety & IDD
ASD / Executive Functioning / Anxiety
DBT & Personality Disorder / IDD
Differential Diagnosis: Mood & Adjustment Disorder
Down Syndrome & Alzheimer's Disease / Dementia
Executive Functioning
IDD & Alzheimer's (Dementia)
OCD & IDD
Sensory Integration
Trauma Informed Care
ADHD / IDD
ASD & ADHD
Bipolar & IDD Disorder
Delusional Disorders & IDD
ID & Schizophrenia
Down Syndrome & Depression
ID / Maintaining and Keeping Friendships
Mood Disorder & ID
Side Effects of Psych. Meds in Individuals with IDD
Individuals at Risk for Aberrant Sexual Expression
Understanding Individuals with ID and Mental Illness

**National START Practice Groups**

As part of the START model and the national START Professional Learning Community, NYSTART personnel 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 of the Center for START Services

## Summary

- Since program inception, the Region 4 Richmond Kings team provided outreach to community partners including mental health providers, residential providers, families and first responders.
- A very positive accomplishment has been the completion of 93 linkage agreements. These are critical to the collaboration and a key component of START's goals aimed at building community capacity. In addition, the program is currently in the process of developing linkage partnerships with volunteer organizations for the Resource Center guests, urban farms and local fitness clubs as well as medical providers, inpatient mental health units, vocational and day service providers, dentists and other experts in the field.
- The team has also been actively using resources from The Center for START Services web-based learning platform to provide additional learning opportunities for team members as well as community providers. They have especially been committed to increasing expertise in the area of trauma as it impacts people with IDD, and will schedule community trainings to share this knowledge.

- The Region 4 Richmond Kings program has been securing social work, psychology, and other mental health interns who will be with the team in the upcoming fall. Efforts have been ongoing to build relationships with several colleges to offer field placements to masters' level social workers and counseling students. This will increase the pool of trained professionals who are able to work with individuals with IDD and complex behavioral health needs.

### Recommendations

- Develop linkage agreements with more community stakeholders to enhance collaborations which will increase the capacity of the system of care in providing supports to people with IDD and significant behavioral health needs.
- Complete work on linkage agreement with Kings County Hospital, OMH and OPWDD that will enhance collaborations for newly developing programs that include a specialized inpatient unit for adults with IDD and a transitional unit serving the same population.
- Track and report specific data for the dates, topics and attendance at trainings at upcoming trainings in FY 2018/2019. This data should be used to identify gaps in training needs. Additional trainings offered should be based on diagnostic and clinical trends identified from the SIRS database.

## 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.B shows the percent of individuals enrolled in the region who received these planned 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 throughout the reporting period.

**Table IV.B. Percent of individuals enrolled receiving START planned services**

| Variable | Children | Adults |
|---|---|---|
| N | 63 | 137 |
| *Utilization of Planned Services (% of Individuals)* | | |
| Outreach | 86% | 99% |
| Intake/Assessment | 92% | 93% |
| CSCPIP | 65% | 80% |
| Clinical Consultation | 44% | 65% |
| Medical Consultation | 25% | 43% |
| Therapeutic Supports | 27% | 26% |
| Crisis Follow-Up | 32% | 45% |

**Table IV.C: Percent of Individuals Receiving Planned START Clinical (Coordination) Services with Completed Assessments Tools and Assessment Tools Up to Date**

| **START Tools** | **Completed (FY 17/18) N = 200** | **Up-to-date N= 176** |
|---|---|---|
| *START Action Plan* | 96% | 81% |
| *Aberrant Behavior Checklist (ABC)* | 100% | 85% |
| *Recent Stressors Questionnaire (RSQ)* | 100% | 98% |
| *Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)* | 98% | 83% |
| *Comprehensive Service Evaluations CSEs Completed* | 4% | - |

## Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item psychopathology rating tool that has been widely used in the assessment of people with IDD. (Aman, Burrow, & Wolford, 1997). 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 least 6 months of START service with at least two ABC scores were included (N=103). The average elapsed time between the two administrations is 8 months.

For those individuals receiving services with at least two administrations in SIRS (n=103) results show that average scores decreased in each subscale as shown in Table IV.

**Table IV.D: ABC Analysis**

| | | Mean Score | | | |
|---|---|---|---|---|---|
| **Richmond-Kings (N=103)** | **Percent with Improvement** | **Initial** | **Most Recent** | **t Stat** | **P(T<=t) one-tail** |
| Hyperactivity/Noncompliance | 68% | 23.58 | 17.48 | 5.75 | <0.00 |
| Irritability/Agitation | 74% | 25.13 | 17.28 | 7.36 | <0.00 |
| Lethargy/Social Withdrawal | 61% | 15.26 | 11.49 | 3.65 | <0.00 |

Alpha=0.05

## Summary

- Data shown in Table IV.B regarding the provision of coordinator planned services reveal that the Region 4 Richmond Kings team is providing regular outreach and other planned services to enrollees, though CSCPIP time is lower than expected for children.
- All individuals who are enrolled in START services participate in an Intake/Assessment process in which the START team gathers important historical and biopsychosocial information about the individual and their 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 initial intake process, including 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. Research of ABC scores for individuals receiving START services indicates that the lethargy and irritability subscales are strong predictors of emergency service use. The Region 4 Richmond Kings team's data for the three main subscales used to assess intervention effectiveness show a significant decrease in the psychopathology ratings following initiation of START services.
- 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 his/her crisis experience. The RSQ is administered at intake and when a person has a crisis contact.
- The START tools are an important part of the provision of secondary levels services and inform treatment planning and training needs for individuals and their support system. The data for Region 4 Richmond Kings shows that these tools are being employed and completed, but there are some individuals for whom the completed assessments are not up to date. For example, as noted, the ABC should be completed every 6 months and the CSPIPs need an annual update at a minimum.
- One important START tool is the Comprehensive Service Evaluation (CSE), which is a comprehensive case review that includes a summary completed for individuals with particularly complex needs and/or stressed systems of care. They can facilitate new case formulations, new systemic perspectives and interventions, and new treatment approaches. It is expected that coordinators will be working on a CSE at all times with a goal of completing multiple CSEs per year. It is estimated that about 15-20% of the caseload would benefit from this in-depth evaluation. The Region 4 Richmond Kings team has a low rate of CSE completion thus far at 4% of cases having had a completed CSE.

## Recommendations

- The Region 4 Richmond Kings leadership should work with coordinators in supervision to ensure that all enrollees have all START tools completed and up to date, and these data are entered into SIRS. Review of

these data should demonstrate increased rates at a level of 90% or greater by the end of the second quarter of 2019.

- Leadership team and supervisors should develop a plan for each coordinator to complete CSEs on a regular basis, track these data and achieve a completion rate of at least 15% by the end of FY 2018/2019 with the goal of 20% of the active caseload receiving these evaluations in the future. Prioritize individuals who are experiencing the highest rate of emergency services use or crisis contacts. START leadership team members could also assist with this process.

## 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.

- *Crisis Contact:* An emergency call received by the START team that requires immediate triage and response, likely resulting in an 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 such as Mobile Crisis Management services or an ER visit.

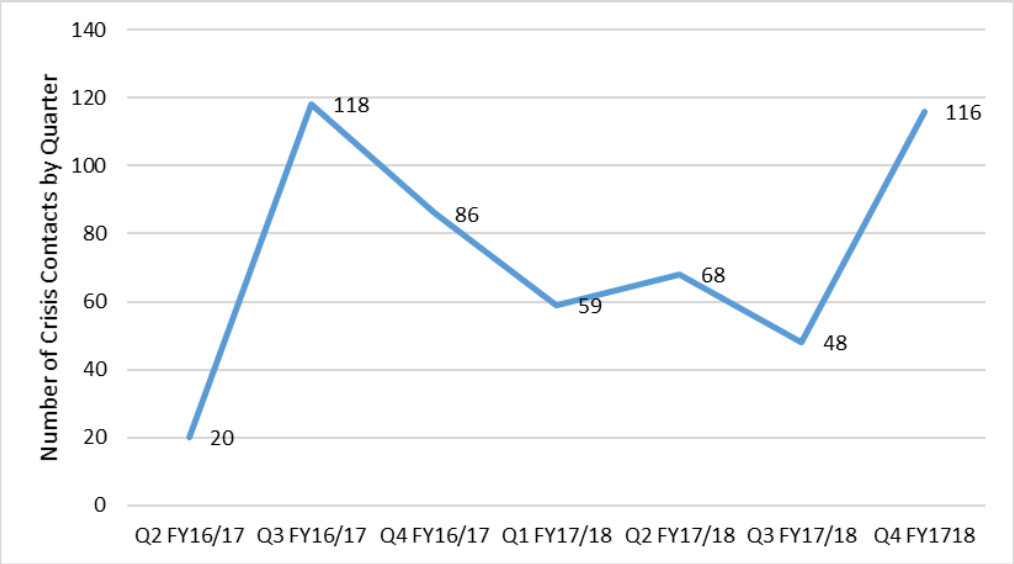
### Crisis Contacts

**Table IV.E: FY17/18 Crisis Contacts**

| Variable | Children | Adults |
|---|---|---|
| *Crisis Contacts* | | |
| Number of Individuals | 17 | 62 |
| Number of Crisis Contacts | 83 | 316 |
| Range of Contacts | (1-26) | (1-53) |
| *Type of Intervention* | | |
| In-Person | 54 (65%) | 155 (49%) |
| Phone Consultation | 29 (35%) | 161 (51%) |
| Missing | - | - |
| *Average Length of In-Person Intervention* | 2.1 hours | 2.1 hours |
| *Crisis Disposition* | | |
| Maintain Setting | 67 (81%) | 234 (74%) |
| Psychiatric Hospital Admission | 3 (4%) | 11 (3%) |
| Emergency Department | 9 (11%) | 52 (16%) |
| Medical Hospital Admission | - | 1 (<1%) |
| START Therapeutic Services | - | 7 (2%) |
| Crisis Stabilization | - | 1 (<1%) |
| Other (Incarcerated, Referral to services, "Other") | 1 (1%) | 5 (2%) |
| Unreported | 3 (4%) | 5 (2%) |

Region 4 Richmond Kings coordinators provide 24-hours crisis response for individuals enrolled in their program. The following chart reflects the number of documented acute crisis calls received by the region by quarter since program inception through the end of fiscal year 18 (March 31, 2018). During the period of this report, Richmond Kings responded to 399 crisis calls from 79 different individuals (40% of population).

**Figure IV.A: Acute Crisis Contact Trends per Quarter**




## Summary

- A number of individuals made use of the START 24-hour crisis response service. Over 3/4 of all individuals were able to remain in their current setting with small numbers ending up in an ED or inpatient psychiatric admission, which at times is an appropriate outcome.
- There were some individuals who had a large number of contacts raising some concern. Individuals who have a large number of crisis contacts should be receiving added outreach, clinical case consultation from the clinical and medical director and potentially START therapeutic supports (Therapeutic Coaching and/or Resource Center services) and these higher numbers (one child having 26 contacts, one adult having 53 contacts) should be mitigated. In some cases, crisis phone contacts are frequent because an enrollee is using this crisis service more as a support similar to a "warm line", and more planned interventions such as regularly scheduled outreach contacts or other supports should replace the regular reliance on the crisis line.
- Despite some frequent utilizers of the START crisis line, the frequency of crisis calls per month has dropped showing the effects of the evolving programs sophistication in applying prevention interventions and outreach to support individuals with a high risk of emergency service use. It is very likely that increasing face-to-face evaluation for crisis calls contributed significantly to the positive trends. This is born out in the data on reductions in the use of these services pre and post START enrollment as well.

## Recommendations

- In person assessments should increase and be occurring in about 70% of all crisis response contacts. The Region 4 Richmond Kings leadership team should meet and review a subset of recent crisis contacts to provide guidance to on call staff regarding the determination that a face=to=face contact is needed.
- Closely examine any cases with multiple crisis contacts that are ongoing and ensure that this individual has adequate prevention and outreach interventions in place. Review these cases with the clinical and medical director and complete a CSE if not already done.

# Section V: START Therapeutic Services

## In-Home Therapeutic Coaching

NYSTART In-Home Therapeutic Coaching is designed to be a short term, therapeutic service provided to an individual in his/her current setting. The need for this service is determined by the Start Coordinator in collaboration with the Clinical Director, Therapeutic Coaching Team Lead, individual and his/her 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. In-home supports can be provided within a variety of settings. Currently, services are provided within a family home, an individual's own home, group homes, day support programs, CPEPs, and residential treatment facilities as part of a transition plan. The goal 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 Therapeutic Coaching Supports**

| Variable | Children | Adults |
|---|---|---|
| *In-Home Therapeutic Coaching* Individuals Served | 13 | 17 |
| Average number of hours (range) | 11 (1-23) | 10 (2-30) |
| Total hours provided | 156 | 184 |
| Percent Emergency Hours | 12% | 10% |

## Resource Center

The following table reflects utilization of the START Resource Center. The program has four beds half of which are designated for planned admissions. Planned admissions are intended to serve adults who live with their families or natural supports and have not been able to use respite in more traditional settings due to ongoing behavioral health concerns. Depending on the needs of the person and his/her family, the frequency and length of planned Center admissions may vary but average about 3 days per admission. The other two beds are designated for emergency admissions, which serve adult enrollees experiencing acute crises. Emergency admissions are longer and average about 20 days, during which time, guests received assessment and individualized intervention and discharge planning.

**Table V.B: Center-Based Supports**

| Variable | Planned Admissions (opened 1/2/2018) | Emergency Admissions (opened 2/26/2018) |
|---|---|---|
| Number of individuals admitted | 18 | 1 |
| Total number of admissions | 33 | 1 |
| Range of days | 1 to 10 | 21 |
| Avg LOS (days) | 5 | 21 |
| Total time spent in resource center (days) | 165 | 21 |
| Number of individuals with more than 1 admission | 10 | 0 |
| Percent of individuals with more than 1 admission | 56% | 0% |
| Occupancy Rate (2 beds) | 94% | 12% |

Summary

- An exciting new addition to the Region 4 Richmond-Kings program is the Resource Center, which opened in January 2018. There has been a focus on recruiting counselors for this program and enhanced training on the MH aspects of IDD for them. The program has developed and is working on mastery of various therapeutic activities used at the center with significant support from the Center for START Services and other START programs across New York state and nationally. One already very successful approach they have adopted is "strength spotting." The Center staff and guests have been noting the positive strengths they see in each other, and this has promoted positive sense of wellbeing. Additionally, the strengths spotting initiative was presented at the START National Training Institute Poster Session and was recognized as an innovative START practice.
- The In-Home Therapeutic Coaching services have also recently launched. This service will be valuable in supporting families and individuals to reduce out of home placements and help keep families together. There are currently 8 coaches as part of this team with plans to hire as many as 12. The program is actively working on developing benchmarks for services in this area. Several areas of importance are being addressed including planning steps to increase caseloads, referrals and increasing the number of coaches; identifying steps to ensure fidelity to the START model; the development of a library of resources; plans for measuring use of strength spotting as a tool in this service; satisfaction measures for individuals and caregivers; and additional data tracking to inform practice in this service area.

Recommendations

- Continue intensive training and expansion of these two new services.
- Continue work on setting up benchmarks and goals for the development of the new services.
- Targets for the Center-based services are to have 2 planned stays (shorter lengths of stays between 2 and 5 days) and 2 crisis stays (length of stays up to 30 days) and overall occupancy rates of a minimum of 85%.

# Conclusions and Recommendations for FY 2018/2019

## Conclusions

The NYSTART Region 4 Richmond Kings program continues to expand and grow. A total of 200 individuals have been served during the reporting period, and a priority will be hiring into vacancies, and continuing to certify all coordinators. This team continues to learn more and to engage more closely with community partners, developing collaborations and linkages that will inform efforts to support individuals with IDD who have significant behavioral health needs. Since program launch, this team has been able to demonstrate reduced emergency service use when START is engaged. Psychopathology ratings also show a trend to improvement following initiation of START services. A wide array of trainings has been provided and the team continues to expand this primary component of service. These efforts, in addition to linkage agreements allow the program to reach and help more people in the key START goal to increase the capacity in the system of care in serving this population.

The Region 4 Richmond-Kings team experienced a few challenges since inception, including hiring and retaining staff. They have developed associations with local colleges and will be having interns, and can seek candidates for coordinator and other positions from institutions graduating individuals with master degrees in related fields. The START tools are being completed but some require updating. Crisis contacts are down but there remain a small number of individuals with multiple contacts who may benefit from added supports such as the newly developing Therapeutic Coaching and Center Based services.

# Recommendations for Fiscal Year 2018/2019

## Program Enrollment

- Continue efforts to fill coordinator vacancies, which will allow expansion of the program with the goal being to reach full capacity (to serve as many individuals in need as possible). Total open cases should include about 20-25 cases per coordinator.
- Work with agency administration and National Center for START Services staff to identify key characteristics for qualified staff. A plan should be developed to actively recruit additional staff as current vacancies undermines the program's ability to grow and serve as an important partner in the emergency safety net for individuals with IDD and behavioral health needs.
- Expand recruitment efforts by reaching out to schools graduating individuals with master's degrees in related fields and increasing advertising. Work closely with the Center for START Services to develop additional strategies to fill positions and stabilize the team's composition.

## Characteristics of Persons Served

- Demographics
    - The Region 4 Richmond Kings team should continue to work on enhancing opportunities for education and training in order to increase cultural and linguistic competency in the coming fiscal year.
- Mental Health and Chronic Health Conditions
    - Continue and expand the scope of trainings for community partners on special issues in diagnosing psychiatric disorders in individuals with IDD.
    - Design specific trainings to teach community partners about the most common medical conditions and medication side effects that may provoke or worsen behavioral and emotional symptoms.

## Emergency Service Trends

- Coordinators should examine their caseload and report during triage if there are any individuals who have had an emergency service. A plan should be developed to increase engagement of START as a way to improve rapport and working relationships with caregivers of individuals enrolled in services.
- Going forward, the following steps should be taken to address this area if not already done for any case with 10 or more crisis calls:
    - Initial review by Clinical Director who should work with coordinator.
    - 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.

## START Clinical Services

***Primary Services***

- Develop linkage agreements with more community stakeholders to enhance collaborations which will increase the capacity of the system of care in providing supports to people with IDD and significant behavioral health needs.
- Complete work on linkage agreement with Kings County Hospital, OMH and OPWDD that will enhance collaborations for newly developing programs that include a specialized inpatient unit for adults with IDD and a transitional unit serving the same population.
- Track and report specific data for the dates, topics and attendance at trainings at upcoming trainings in FY 2018/2019. This data should be used to identify gaps in training needs. Additional trainings offered should be based on diagnostic and clinical trends identified from the SIRS database.

***Secondary Services***

- The Region 4 Richmond Kings leadership should work with coordinators in supervision to ensure that all enrollees have all START tools completed and up to date, and these data are entered into SIRS.
- Review of these data should demonstrate increased rates at a level of 90% or greater by the end of the second quarter of 2019.
- Leadership team and supervisors should develop a plan for each coordinator to complete CSEs on a regular basis, track these data and achieve a completion rate of at least 15% by the end of FY 2018/2019 with the goal of 20% of the active caseload receiving these evaluations in the future. Prioritize individuals who are experiencing the highest rate of emergency services use or crisis contacts. START leadership team members could also assist with this process.

***Tertiary Services***

- In person assessments should increase and be occurring in about 70% of all crisis response contacts. The Region 4 Richmond Kings leadership team should meet and review a subset of recent crisis contacts to provide guidance to on call staff regarding the determination that a face=to=face contact is needed.
- Closely examine any cases with multiple crisis contacts that are ongoing and ensure that this individual has adequate prevention and outreach interventions in place. Review these cases with the clinical and medical director and complete a CSE if not already done.

***Therapeutic Supports***

- Continue intensive training and expansion of these two new services.
- Continue work on setting up benchmarks and goals for the development of the new services.
- Targets for the Center-based services are to have 2 planned stays (shorter lengths of stays between 2 and 5 days) and 2 crisis stays (length of stays up to 30 days) and overall occupancy rates of a minimum of 85%.