# NYSTART Region 3

FY17 (April 2016 – March 2017)

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

**Prepared for**
The New York Office for People With Developmental Disabilities

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# Annual Report

# 2017

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# Executive Summary

OPWDD has embarked on the development and roll out of NYSTART, a best practice, evidence-informed tertiary care program and community network to enhance capacity toward effective support for individuals with IDD and behavioral health needs. NYSTART Region 3 was one of the first programs to be developed in the state, covering the Capitol, Taconic, and Hudson Valley Regions.

The mission of NYSTART (Systemic, Therapeutic, Assessment, Resources, and Treatment) is *"to increase the community capacity to provide an integrated response to people with intellectual/developmental disabilities and behavioral health needs, as well as their families and those who provide support. This will occur through cross systems relationships, training, education, and crisis prevention and response in order to enhance opportunities for healthy, successful and richer lives".* In collaboration with OPWDD and other state partners in NY, NYSTART Region 3 has worked since 2104 to ensure the successful implementation of this model in order to meet the needs of individuals with IDD and behavioral health needs within the changing system of supports.

In collaboration with the National Center for START Services at the Institute on Disability, University of New Hampshire, NYSTART Region 3 has worked to implement with fidelity to the START model. An essential aspect of the model, is collection of data. Through the START Information Reporting System (SIRS), all elements of service delivery along with de-identified information about service users are entered into a database in order to evaluate NYSTART outcomes and compare those to national trends. The report to follow provides a detailed analysis of NYSTART Region 3 for the 2016-2017 fiscal year.

The START model requires that staff be certified as "START Coordinators" through the National Center for START Services to ensure that they have the expertise needed to provide NYSTART services and training. Recruitment and retention of Coordinators has been a challenge, as it is in many new programs. At this time 9 current team members have successfully completed requirements and are now certified START Coordinators. This means that they can work independently to use the tools of NYSTART and are trained as trainers in the MH Aspects of IDD.

During the current reporting period, 82 individuals were newly enrolled with NYSTART Region 3, and a total of 255 individuals were served. New enrollments were lower for this reporting period resulting in lower overall caseload at the end of the reporting period compared to previous year. NYSTART Region 3 has a smaller percentage of children referred than is seen nationally, with most of the children having an autism spectrum disorder. Most children live at home with families, while over half of the adults live in group home settings. These trends impact the outreach and linkages that are needed in this region. In-home therapeutic supports, which are not yet available in Region 3, would increase the capacity of START to effectively support families with children. These supports, along with a Resource Center, are needed to increase capacity and provide a more comprehensive array of supports, especially for families.

Service outcomes continue to be positive with reductions in emergency service use seen in both the child population and the adult population. NYSTART Region 3 has already been beneficial to a system that has historically relied on emergency departments, especially for children. While this continues to be an area of focus, substantial strides have been made. These trends will continue to be tracked.

NYSTART Region 3 has made progress in several areas over the last reporting period and continues to work on areas including crisis response, crisis planning, and outreach to families. The team continues to work collaboratively with OPWDD Regional and Central Offices, community partners, and the Center for START Services to ensure fidelity to the model.

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NYSTART Region 3 Program

# Recommendations from 2016 Annual Report/Progress

1. To increase community training to build capacity of the system to support individuals in their homes and communities.

    - Region 3 has increased efforts to provide community trainings over this reporting period. All hubs are utilizing Moodlerooms trainings, especially those focused on trauma informed care, to help train teams in working with the individuals we serve. The program also developed a presentation that provides a clinical overview of working with individuals with IDD and co-occurring mental health conditions. This training was reviewed and approved through OPWDD Central Office and has been very well-received by providers throughout the 18-county region. Region 3 also continues to provide an *Introduction to NYSTART* training to help community members understand the role NYSTART plays in working with individuals and their teams.
    - Additionally, in partnership with OPWDD's Central Office and the Institute for Police, Mental Health and Community Collaboration, Region 3 is very involved in Crisis Intervention Team (CIT) training. The START Clinical Director, has overseen the role of START in this training and has had the opportunity to present to numerous local, state and county law enforcement agencies through this collaboration.
    - Documented community outreach nearly doubled from the previous fiscal year to over 200 episodes.
    - Region 3 is ambitiously partnering with 4 area colleges to develop a Field Placement program for baccalaureate level social workers at each of the program's hubs. To date, 5 student interns have been identified and will begin in the fall, 2017: 2 in the Capital District, 2 in Taconic and 1 in Hudson Valley. This is an exciting opportunity to expose undergraduate social workers to macro level work and working with individuals with IDD and complex behavioral health issues and their teams.

2. The program will continue to work to assure that all team members who are in positions requiring coordinator certification achieve necessary competencies and milestones with the goal of obtaining coordinator certification.

    - During this reporting period eight coordinators achieved national coordinator certification.
    - The need to provide an opportunity for new/uncertified coordinators to meet requirements was identified. Thus, a certification study group was established. This group is facilitated by Laurie Hoagland, Team Leader, and Amy Anneling, Clinical Director, and meets twice per month. These sessions allow coordinators who are working toward certification an opportunity to support one another and to learn about the process together.
    - 8 coordinators are in various stages of certification preparation, 7 of whom will be scheduled for their certifications during the next reporting period.

3. Develop a plan to assure that all assessments are administered and entered into SIRS within the required timeframes.

    - One major performance improvement project that began in May, 2016, was to improve documentation and SIRS data entry. The Region 3 leadership team increased focus on in this area and numerous SIRS trainings occurred between June, 2016 and March, 2017 and frequent discussions during staff meetings occurred to reinforce documentation requirements and the need to enter information into SIRS in a timely manner. These efforts clearly helped Region 3 coordinators understand the expectations for performing assessments, completing documentation and timely entering of data into SIRS. The most recent data indicates that documentation of assessments has increased by 20% and for our current active caseload, documentation of assessments now exceeds the standards for certified START programs.

4. Develop a plan to improve the completion of Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs) and Comprehensive Service Evaluations (CSEs) for individuals enrolled.

    - The completion of Cross System Crisis Prevention and Intervention Plans (CSCPIP's) increased by 23% during this reporting period, which is a notable improvement. The most recent review of the region's current caseload reveals a CSCPIP completion rate of about 86%, which exceeds certification standards. Additionally, most of the crisis plans are currently up-to-date. Having an annually updated crisis plan is a key element of fidelity to START.

    - Dr. Anneling, Clinical Director, has begun a performance improvement project to increase the completion rate of Comprehensive Service Evaluations (CSE's). Up until now, the focus for CSE completion has been on those required for certification. She is working with each certified coordinator to ensure that the need for a CSE is being identified for at least one individual on each coordinator's caseload and that coordinators are focusing attention on the completion of this very valuable product.

5. Continue to work with state and regional OPWDD liaisons to develop an implementation plan for in-home mobile and center based therapeutic supports within the region.

    - An Ulster Greene ARC building in Kingston, New York has been identified as the future site for the Resource Center and architectural drawings have been completed and approved. The renovation/construction job went out for bids in spring, 2017 and rehabilitation of the building is expected to be complete by September 1, 2017.

    - It is the goal of the Region 3 START Program to fully implement the START model, including both the Resource Center and In-home Therapeutic Coaching. The Region 3 Program and OPWDD are moving forward with the coordination of efforts with provider networks to provide these services in the future.

6. Continue to work with mobile crisis teams throughout the region to utilize the NYSTART program as a resource. Provide regular training and opportunities for outreach to providers.

    - Region 3 has met with many of the mobile crisis teams throughout the region and are regular members of numerous community/countywide meetings with focus on increasing the capacity of the service delivery system in relation to services for individuals with IDD and co-occurring behavioral health needs.

    - By attending these meetings and being members of countywide planning meetings Region 3 had the opportunity to clarify and identify NYSTART's role in partnering with mobile crisis teams throughout the region, specifically those in Warren/Washington, Albany, Ulster, Dutchess and Rockland counties.

7. Development of linkage agreements

    - There is an ongoing focus on improved collaboration between START and mobile crisis programs throughout the region.
    - Improved collaboration and linkage with community hospitals has also occurred during the past reporting period.
    - The NYSTART Region 3 Director participated in a 6-month professional learning community on networking and linkage agreements sponsored by the Center for START Services and hosted by Susan Morris, RN. This learning group provided an opportunity for all START teams to learn from one another and identify clear strategies to improve the linkage agreement process.

8. Improve overall timeliness and accuracy of data collection of all services in order to track and evaluate outcomes for individuals enrolled in the START program.

    - Data collection in all areas has improved significantly in the past fiscal year. Currently, all data meets or exceeds expectations for certified START programs.

# Findings

The following report provides an analysis of enrollment, demographic and service outcome data for the Region 3 NYSTART program for fiscal year 2017 (April 1, 2016- March 31, 2017).

All descriptions of enrollment trends, characteristics of persons served, emergency service trends, and service outcomes of those served by NYSTART Region 3 are based on data entered into the START Information Reporting System (SIRS) by program staff. The Region 3 program serves individuals across the lifespan from ages 6 and up.

## Section I: Program Enrollment

Data below reflect all individuals who have enrolled in NYSTART Region 3 and received services since the program first began (N=429). Individuals who declined services or were ineligible for START services were referred to alternative services and not included in this report.

**Table I.A: Enrollment Trends: Adults (18+ years old)**

| | FY15* (9/14-3/15) | FY16 (4/15-3/16) | FY17 (4/16-3/17) |
|---|---|---|---|
| Total Caseload at Beginning of Reporting Period | 0 | 134 | 191 |
| Individuals **Enrolled** During Reporting Period | 150 | 122 | 64 |
| Individuals **Inactivated** During Reporting Period | 16 | 65 | 108 |
| Total Caseload at End of Reporting Period | 134 | 191 | 147 |
| **Individuals Served During Reporting Period** | **150** | **256** | **255** |
| **Percentage of Total Caseload** | **81%** | **78%** | **79%** |

**Table I.B: Enrollment Trends: Children (6 -17 years old)**

| | FY15* (9/14-3/15) | FY16 (4/15-3/16) | FY17 (4/16-3/17) |
|---|---|---|---|
| Total Caseload at Beginning of Reporting Period | 0 | 34 | 49 |
| Individuals **Enrolled** During Reporting Period | 36 | 39 | 18 |
| Individuals **Inactivated** During Reporting Period | 2 | 24 | 35 |
| Total Caseload at End of Reporting Period | 34 | 49 | 32 |
| **Individuals Served During Reporting Period** | **36** | **73** | **67** |
| **Percentage of Total Caseload** | **19%** | **22%** | **21%** |

*First enrollments began in September 2014*

**Figure I.A: Enrollment Trends by Fiscal Quarter**

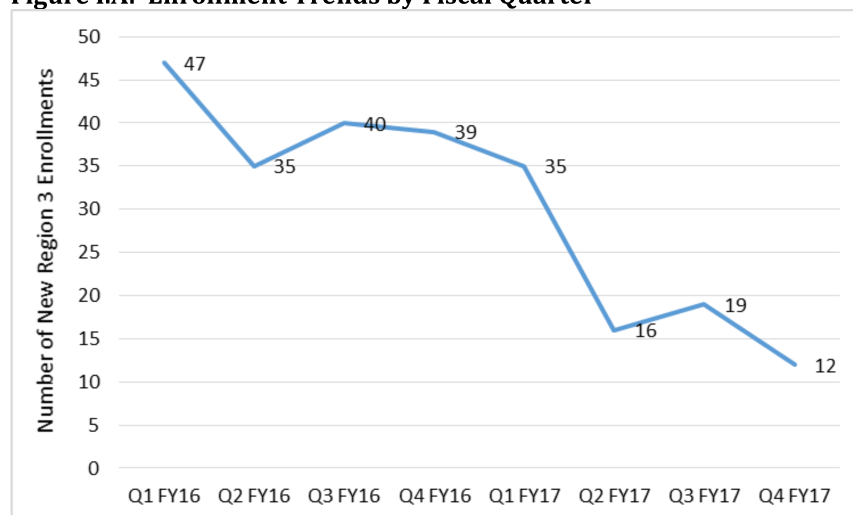


**Table I.C: Reasons for individuals becoming inactive* during FY17**

**The term "Inactive" is used to describe an individual who had been enrolled but is no longer receiving ongoing START services because their situation changed. The average Length of Stay (LOS) in NYSTART Region 3 was 15 months during FY17 which falls within the National average of 12 – 18 months.*

| | Adults | Children | Total N | Overall Frequency |
|---|---|---|---|---|
| Stable functioning | 69 | 13 | 82 | 57% |
| No longer requesting services | 24 | 8 | 32 | 22% |
| Moved out of START region | 8 | 4 | 12 | 8% |
| Unable to Contact | 5 | 7 | 12 | 8% |
| Inappropriate for services | 2 | 1 | 3 | 2% |
| Deceased | | 1 | 1 | 1% |
| Long-Term Residential Placement | | 1 | 1 | 1% |
| **Total Number of Individuals Inactive** | **108** | **35** | **142** | **100%** |

**Table I.D: Sources of referral (new enrollments only)**

| | Adults | | Children | |
|---|---|---|---|---|
| Variable | **FY16** | **FY17** | **FY16** | **FY17** |
| *N* | 122 | 64 | 39 | 18 |
| *Referral Source* (%) | | | | |
| Case Manager | 61% | 66% | 64% | 67% |
| Emergency Department | 6% | 3% | 3% | 6% |
| Family Member | 9% | 11% | 5% | 6% |
| Residential/Day Provider | 12% | 13% | 10% | 17% |
| Other (Mobile Crisis, School) | 11% | 8% | 15% | 6% |
| Missing | 1% | **0%** | 3% | **0%** |

**Table I.E: Reasons for enrollment (new enrollments only)**

| | Adults | | Children | |
|---|---|---|---|---|
| Variable | **FY16** | **FY17** | **FY16** | **FY17** |
| N | 122 | 64 | 39 | 18 |
| *Most Common Reasons for Enrollment (%)* | | | | |
| Aggression | 78% | 84% | 83% | 85% |
| Family Needs Assistance | 13% | 18% | 45% | 42% |
| Risk of losing placement | 11% | 12% | 2% | 4% |
| Mental Health Symptoms | 41% | **49%** | 28% | **35%** |
| Suicidality | 19% | **22%** | 4% | **10%** |
| Self-Injurious Behavior | 26% | 33% | 23% | 29% |

## Summary

- Enrollment trends for adults and children in Region 3 has been consistent since the inception of the program. Children have made up about 20% of enrolled individuals since 2015. This is lower than what lifespan START programs typically experience. This points to a continued need for ongoing outreach and linkage development with traditional children's' services in the community.
- As seen in Figure 1, the number of referrals in fiscal year 17 has decreased significantly when compared to previous years. This is due to the program transitioning to a "closed system" which provides crisis response

services only to individuals enrolled in on-going START services. In addition, the program also experienced an enrollment hold during the months of January through March 2017.

- Case managers have been the primary source of referral to Region 3 for both children and adults since program inception. For the current fiscal year, case managers made over 60% of referrals for both adults and children. Referrals from family members have increased slightly for adults to just over 10% of new referrals. For children, the percentage of referrals from families is about 6%. However, referrals for children from community providers increased over the previous fiscal year to 17%.
- Aggression continues to be the primary reason for enrollment for both adults and children to NYSTART, however, the percentage of individuals reporting aggression in Region 3 (84%) is higher than national START data (74%).
- The percentage reporting mental health symptoms as reason for referral (49% for adults and 35% for children) is higher than national trends. This is an increase from the previous FY. Even though externalizing issues are reported at high rates, there also seems to be an understanding of the connection to the mental health status of the individual.
- Children who are enrolled were more likely than adults to be referred because their family was in need of assistance. This trend makes sense since enrolled children are more likely to reside with their families than adults

## Recommendations

- While the percentage of children enrolled in the Region 3 program remains consistent across years, it is unclear as to whether the caseload make up (80% adults and 20% children) mirrors what is seen in all Region 3 OPWDD services or if additional and continued strategic outreach, linkage and education to providers and stakeholders that traditionally serve children in the region is needed. The START program should also work with the OPWDD regional office to gain more insight into enrollment trend and determine whether there are untapped referral resources in the region.

# Section II: Characteristics of Persons Served

## Demographics

Section II of this report provides demographic and diagnostic trend data for all individuals served by NYSTART Region 3 (N=322) during FY17 (April 1, 2016-March 31, 2017). There are no significant differences in the demographics of active individuals in FY17 compared to previous fiscal years. When relevant the Region 3 population is compared to the START population from other lifespan programs.

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

| | Adults | | Children | |
|---|---|---|---|---|
| *Variable* | **FY17:R3** | **Other Lifespan** | **FY17:R3** | **Other Lifespan** |
| *N* | 255 | 2743 | 67 | 463 |
| *Age* (Mean) | 29 | 30 | 13 | 13 |
| *Gender* (% male) | 60% | 61% | **81%** | **76%** |
| *Level of Intellectual Disability* (%) | | | | |
| No ID/Borderline | 9% | 7% | 14% | 16% |
| Mild | 59% | 49% | 30% | 39% |
| Moderate | 22% | 28% | 25% | 25% |
| Severe-Profound | 6% | 9% | 11% | 7% |
| None Noted | 4% | 7% | 19% | 14% |
| *Living Situation* (%) | | | | |
| Family | 30% | 36% | 83% | 85% |
| Group Home and Community ICF/DD | **53%** | **31%** | 4% | 6% |
| Independent/Supervised | 7% | 7% | 0% | |
| Psych. Hospital/IDD Center | 3% | 4% | 6% | 3% |
| Other (Jail, Homeless, "Other") | 5% | 17% | 4% | 2% |
| Missing | 1% | 5% | 4% | 4% |

## Summary

- The gender distribution for adults (age 18 and older) is roughly 60% male and 40% female which is consistent with START programs nationally. For children (under the age of 18) however, the gender distribution is higher than the National average with over 80% male and under 20% female. This may be related to the high percentage of children with ASD since males have a higher incidence of ASD diagnosis.
- In Region 3, adults are about 20% more likely to live in a group home than adults in other START programs nationally. This trend has been consistent in this region since inception.
- 83% of children enrolled in Region 3 services live with their families, which is consistent with the national average of 85%.

## Recommendations

- Although the high percentage of both children and adults residing in supervised settings is a trend that has been identified since the inception of the program, it is important to continue to monitor and understand. A primary goal of START is to support individuals in their natural, family settings and therefore more outreach to families and service providers should be done in order to receive referrals prior to out of home placement whenever possible.

- One service that may promote referral to START prior to out of home placement is In-home therapeutic supports. The Region 3 program does not yet offer this service but continues to work with OPWDD Central Offices to develop a plan to implement these services.

## Mental Health and Chronic Health Conditions

It is critical to understand each service recipients' presentation in the context of their biological, psychological, and social strengths and concerns. In order to provide intervention and supports, we must know how these factors impact the person and his/her functioning, and specifically how they may contribute to or help prevent crisis and instability. An accurate understanding of both mental health and medical conditions is imperative in designing effective crisis prevention and intervention services.

Changes made to diagnostic criteria categories in the new DSM5 (Diagnostic and Statistical Manual of Mental Disorders) resulted in an important update to how mental health conditions were categorized and reported in SIRS. Because of this recent update, MH condition trend data is not available for this reporting period. However, trends in the identification of mental health conditions have been consistently high in Region 3 and a comparison of the frequency of diagnostic categories between Region 3 and other START programs is available.

It is also important to note that these diagnoses are reported by the individual's team. The presence of multiple diagnoses may indicate uncertainty and the START teams may be able to assist the system through assessments, service evaluations and consultation.

**Table II.B: Mental health conditions**

| | Adults | | Children | |
|---|---|---|---|---|
| Variable | **FY17:R3** | **Other Lifespan** | **FY17:R3** | **Other Lifespan** |
| *N* | 255 | 2743 | 67 | 463 |
| *Mental Health Conditions* (%) | | | | |
| At least 1 diagnosis | 88% | 78% | 67% | 70% |
| Mean Diagnoses | **4.9** | **1.9** | 1.9 | 2.1 |

**Figure II.A: Frequency of mental health conditions for enrolled adults**

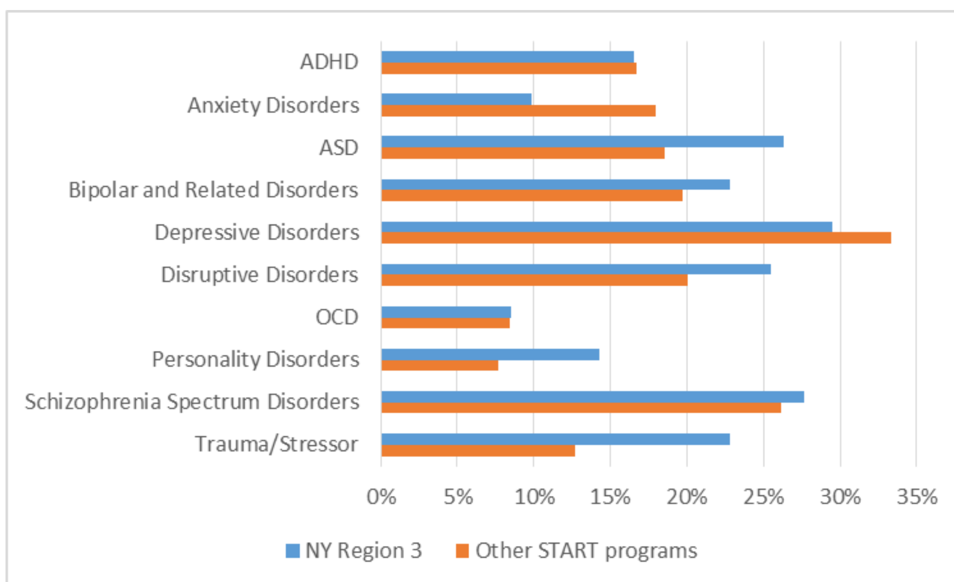
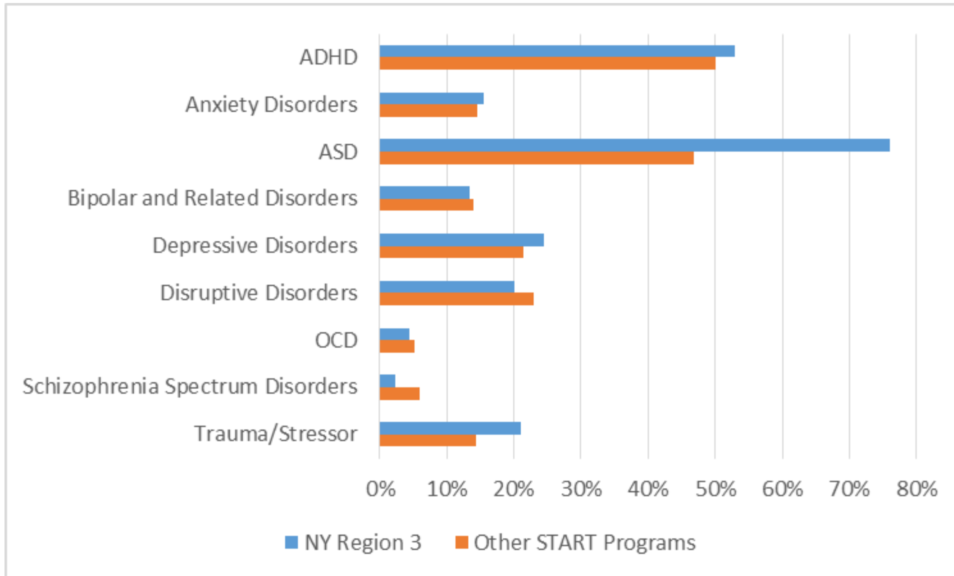


**Figure II.B: Frequency of mental health conditions for enrolled children**




## Summary

- Of the individuals who are diagnosed with a mental health condition, 65% report more than one condition. This is similar to national data.
- The average number of MH conditions reported in Region 3 is 4.9, which is more than double that of other START programs.
- The most common conditions diagnosed for adults enrolled in services were trauma, schizophrenia spectrum disorders and ASD.
- Both children and adults enrolled in Region 3 are more likely than the national START Network to be diagnosed with trauma or ASD.

## Recommendations

- The frequency of PTSD and trauma related disorders, schizophrenia spectrum disorders and ASD identify a need for the program to structure community trainings, outreach and Community Education Teams meetings to focus on building community capacity to support individuals experiencing these conditions.
- It would also be beneficial for the Region 3 program to identify partners in the community to support children with Autism Spectrum Disorder and their families.

## Chronic Health Conditions

In addition to mental health conditions, many of the individuals referred for NYSTART services present with co-occurring medical conditions. Medical conditions are important to address as research suggests that they are often underdiagnosed, underreported, or signs/symptoms of medical conditions are misinterpreted as challenging behavior and/or mental health conditions.

**Figure II.C: Chronic health conditions**

| | Adults | | Children | |
|---|---|---|---|---|
| Variable | **FY17:R3** | **Other Lifespan** | **FY17:R3** | **Other Lifespan** |
| *N* | 255 | 2743 | 67 | 463 |
| *Chronic Medical Conditions* (%) | | | | |
| At least 1 diagnosis | 73% | 63% | 52% | 53% |
| Mean Diagnoses | **3.7** | **2.0** | 1.5 | 1.6 |

**Figure II.C: Frequency of chronic medical conditions for enrolled adults**

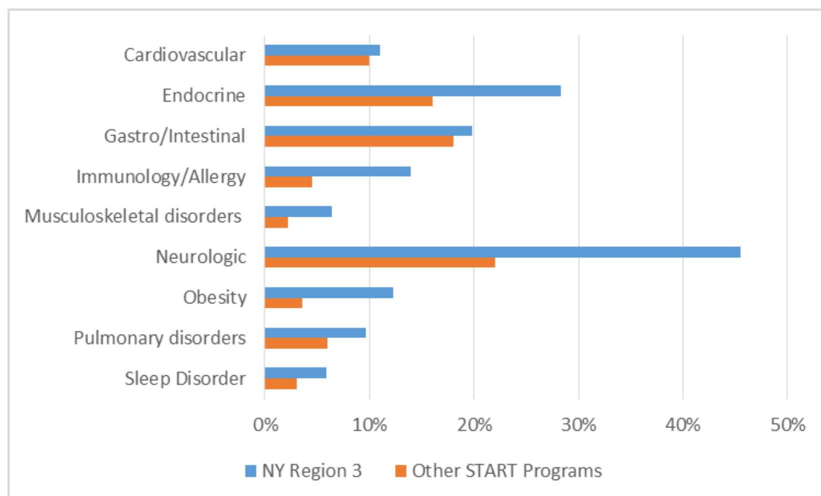
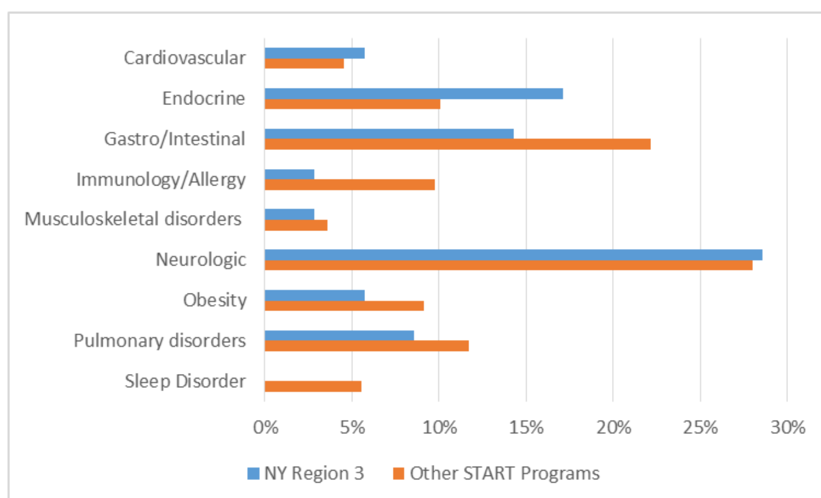



**Figure II.D: Frequency of chronic medical conditions for enrolled children**



## Summary

- Chronic medical conditions were reported for 69% of the individuals served, which is 14% higher than the national START population (55%).
- As with mental health conditions, the average number of chronic health conditions for adults in Region 3 is higher than in other START programs. This trend needs to be monitored.
- Adults in Region 3 are over 20% more likely to be diagnosed with neurological conditions than adults in other START programs. This is not true for children and will be monitored.
- More individuals in Region 3 live in state operated residences. It is unclear as to whether state required documentation promotes more consistent and accurate reporting of medical conditions, resulting in the higher documented rates for individuals enrolled in START.

## Recommendations

- Overall, Region 3 reports higher rates of co-morbid medical conditions for individuals enrolled in services. Ongoing monitoring of these trends is recommended. One strategy to learn more about this trend is to work with the START Medical Director and Nurse to complete more in-depth record reviews.

## Section III: Emergency Service Trends

A number of NYSTART Region 3 service recipients have a history of emergency service use prior to enrollment in START services. The following table presents emergency service trends for individuals at the time of enrollment into services as well as emergency service utilization for individuals while enrolled in START. A target goal of the START program is to help avoid unnecessary emergency service use and reduce recidivism rates. The preliminary findings show a significant decrease in psychiatric hospitalization rates and emergency department utilization for enrolled individuals.

**Table III.A: Emergency Service utilization**

| | Adults | Children |
|---|---|---|
| *N* | 255 | 67 |
| *Psychiatric Hospitalizations* | | |
| **Prior to enrollment**, N (%) | 98 (38%) | 29 (43%) |
| Mean (range) | 1.5 (1-4) | 1.5 (1-3) |
| Percent with Multiple Admissions | 40% | 35% |
| **During START,** N (%) | 33 (13%) | 7 (10%) |
| Mean (range) | 1.4 (1-5) | 1.1 (1-2) |
| Percent with Multiple Admissions | 24% | 14% |
| *Emergency Department Visits* | | |
| **Prior to enrollment**, N (%) | 120 (47%) | 34 (52%) |
| Mean (range) | 3.1 (1-15) | 2.7 (1-10) |
| Percent with Multiple Visits | 57% | 53% |
| **During START,** N (%) | 78 (31%) | 8 (12%) |
| Mean (range) | 2.2 (1-8) | 1.6 (1-4) |
| Percent with Multiple Visits | 51% | 50% |

### Summary:

- Children in Region 3 are slightly more likely to experience emergency room visits and/or psychiatric hospitalizations prior to enrollment than adults also receiving services.
- The percentage of children experiencing hospitalizations and emergency department use is higher than the national averages. The number of children being supported by Region 3 is small so it is difficult to interpret. However, it may indicate that families are unable to reach out for supports until they are in more acute crisis.
- In the year prior to enrollment in START services, about 40% of service users in Region 3 had a history of psychiatric hospitalization. Following enrollment in START services, less than 13% of Region 3 service users were hospitalized for psychiatric reasons during this reporting period. In addition, the percent of individuals with multiple admissions dropped for both adults (16%) and children (21%). Similar trends are seen in START Programs across the country.
- Psychiatric hospitalization trends both pre and post enrollment have been quite consistent over the life of the program. This suggests that maintaining fidelity to START service elements such as comprehensive assessment and evaluation, cross system crisis planning, outreach and emergency response can be effective in improving the outcomes for individuals enrolled in services.
- Emergency Department utilization is often seen as a measure of stability for the individual and system. Prior to enrollment, 48% of individuals in Region 3 had a history of one or more emergency department visits. Following enrollment, only 27% of individuals active during the fiscal year have visited the emergency department, suggesting that involvement with START creates alternatives to emergency department use when an individual experiencing an acute crisis.

Recommendations:

- While the rate of enrollment for children in Region 3 is lower than the START national average, emergency service trends for children enrolled identify a need for START's involvement. It is important that the START program in Region 3 develop a strategic plan to provide outreach and education to stakeholders in the children's service system.

# 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 (CET's), education, system linkage, and community training;

**Secondary (specialized direct services to people at risk of needing emergency services):** intake and assessment activities, comprehensive service evaluations (CSE's), outreach, clinical and medical consultation, and cross systems crisis prevention and intervention planning (CSCPIP); 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.

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 NYSTART Region 3 team members during FY17 as compared to previous fiscal year. Primary START services include system linkages, clinical consultation, education and community training. These services are part of the plan to improve the capacity of the system as a whole so that the community system is 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 MH conditions and continues to engage the system to become active participants in the START learning community.

**Table IV.A Community training activities**

| Primary Services | FY16 | FY17 |
|---|---|---|
| *Community Training and Outreach* | | |
| Community Education/linkage | 49 | 152 |
| Community-based training | 41 | 31 |
| Host Advisory Council Meeting | 9 | 7 |
| Provided training to day provider | 2 | 1 |
| Provided training to emergency services | 2 | 2 |
| Provided training to family | 2 | 2 |
| Provided training to other | 6 | 9 |
| Provided training to residential provider | 1 | 7 |
| Provided training to state facilities (state hospitals, developmental centers) | 1 | 1 |
| Provided training to therapist/mental health providers | 1 | 3 |

| | | |
|---|---|---|
| Transition Support/Planning-Developmental Center | 0 | 2 |
| Transition Support/Planning-Psychiatric Hospital | 1 | 2 |
| **Total Outreach Episodes** | **115** | **219** |
| *Total Linkage/Collaboration Agreements* | **37** | **37** |
| *Clinical Education Team (CET)* | **10** | **9** |

The following is a list of training provided to the community as part of the primary services provided by the region during FY17.

- Introduction to Start
- Crisis Intervention Team training (law enforcement)
- Mental Health and IDD
- Trauma Informed Approaches/PTSD
- EMDR/PTSD
- OCD/ASD
- Reactive Attachment Disorder
- Executive Functioning
- Transitions
- Applied Behavior Analysis/Functional Behavior Assessment
- Reactive Attachment Disorder and Treatment Approaches in Adults
- Trauma and IDD
- Autism Spectrum Disorder
- Fragile X
- Genetic Testing – Drug Metabolism
- Lead Poisoning and IDD
- Sensory Integration
- Mood Disorders and Mental Health
- Traumatic Brain Injury
- Outpatient Mental Health Services, Emergency Mental Health, Mobile Crisis
- Communication deficits and supportive behavioral interventions
- Schizophrenia
- Communication Strategies, Executive Functioning, and IDD
- Communication and Information Processing Delays
- Dementia and Interventions to Support an Individual
- Impulse Control Disorder, Executive Functioning, and Effective Communication
- Childhood Trauma

- Transition Planning
- Schizoaffective Disorder
- Borderline Personality Disorder, Dialectical Behavior Therapy, and IDD
- Body Dysmorphic Disorder
- Dialectical Behavior Therapy
- Social Stories
- Positive Behavior Supports
- Positive Psychology
- Executive Functioning/Frustration Tolerance/Coping Skills
- Alternative Therapies for Individuals with IDD and Trauma
- Traumatic Brain Injury and Executive Functioning
- ASD and adolescent development
- Velocardiofacial Syndrome
- PTSD and the Brain
- ASD and Medication Interventions
- Premature Birth and Effects on the Brain
- Simpson Golabi Behmel Syndrome
- Effects of Prenatal Substance Exposure
- Effects of Polysubstance Abuse
- Agenesis of the Corpus Callosum
- Using Clozapine
- Noonan's Syndrome

**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 insure 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

- Total outreach efforts have dramatically improved from 115 in FY16 to 219 in FY17, due to an increase in communication education/linkage offered on the part of the Region 3 program.
- Members of the Region 3 program are active participants in the national START practice groups.
- The number of linkage agreements has not changed since FY16.

## Recommendations

- Provide the Mental Health and IDD training to every emergency room and inpatient psychiatric unit in our region. We purchased several copies of the DM ID 2 manuals to share with settings we present to, in an effort to aid staff at those settings to feel more comfortable and knowledgeable when working with the dually diagnosed population.
- Modify the Mental Health and IDD training, which, at present, is tailored more toward mental health providers, by creating a similar training for IDD providers and one for direct support professionals.
- Utilize technologies available to us to reach a broader audience and expand the availability of START trainings to more providers. For example, we would like to offer our trainings via WebEx, which would allow flexibility for participants to view the trainings from their own computers/phones - in their offices, remotely, or in large group settings. This also will allow NYSTART staff an opportunity to provide more trainings to larger audiences without having to travel far distances to provide the trainings one at a time to our community partners.
- Partner with the Performing Partner System's throughout the region to assist in offering/providing the Mental Health and IDD training. Addressing the Medicaid population with behavioral health diagnoses is a key component of DSRIP, as it has been shown that this population has the majority of avoidable hospital use, not only because of the behavioral health diagnoses but also because of medical diagnoses that are not being well addressed in the current health care system in NYS. The MH/IDD training is in-line with DSRIP's mission in increasing the capacity of the workforce and decreasing emergency and inpatient hospital utilization.

## 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 are tracked in SIRS. Since Region 3 does not yet provide therapeutic supports, this variable is not included.

- *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 in which the START Coordinator provides education or outreach to the system of support related to general issues or those specific to the individual referred. 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*: START Coordinators will present cases to their teams, and then share clinical consultations provided by the Clinical Director and Medical Director with community team members who support individuals, and work with the Clinical Director to provide direct, on site clinical case consultations.
- *Medical Consultation:* This includes any consultation provided by the START Medical Director regarding medication and other medical issues, includes collaboration with prescribing doctor.
- *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.
- *Planned Center Based (Therapeutic Resource Center)or In-Home Therapeutic Supports*: All of the 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.

Figure IV.A details the percentage of time spent on each planned, secondary service category by Region 3 during the FY, the figures below show the percent of individuals enrolled in the region who received these planned services. Since each individual enrolled in START is at a different stages of case activity and has unique strengths and needs, not all individuals received all planned services throughout the reporting period.

**Figure IV.A: START Services: Percent of Time**

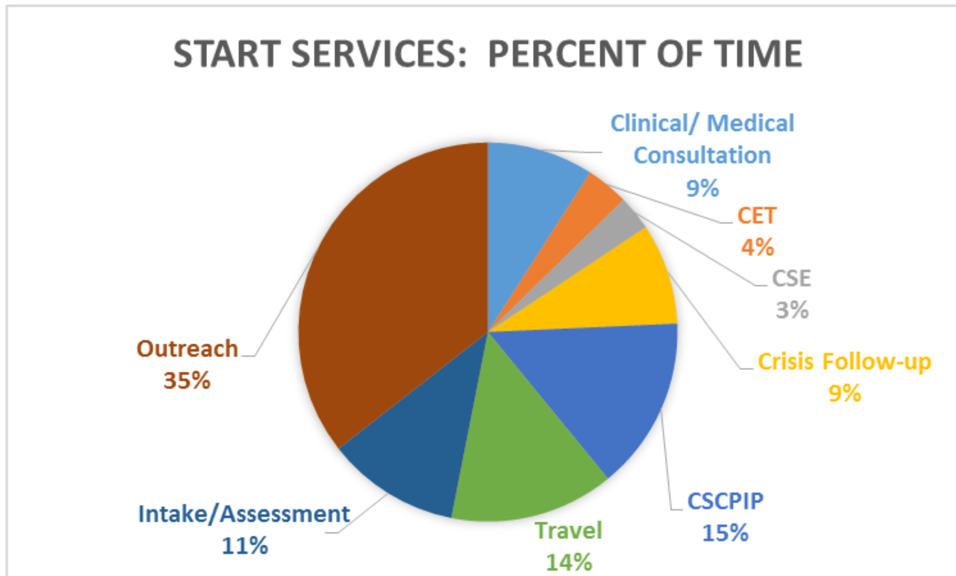


**Figure IV.B: Planned Service Utilization Trends (Percent of Adults)**

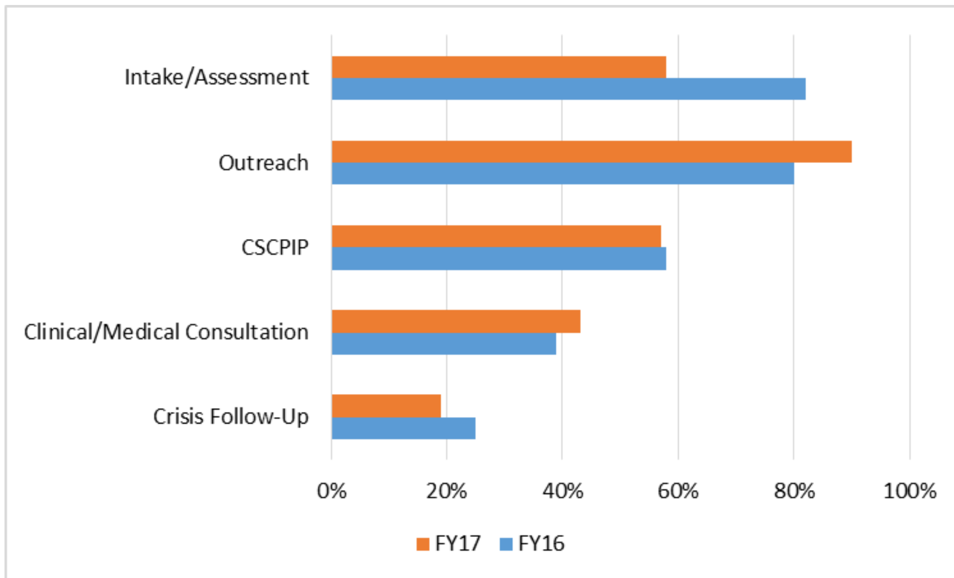
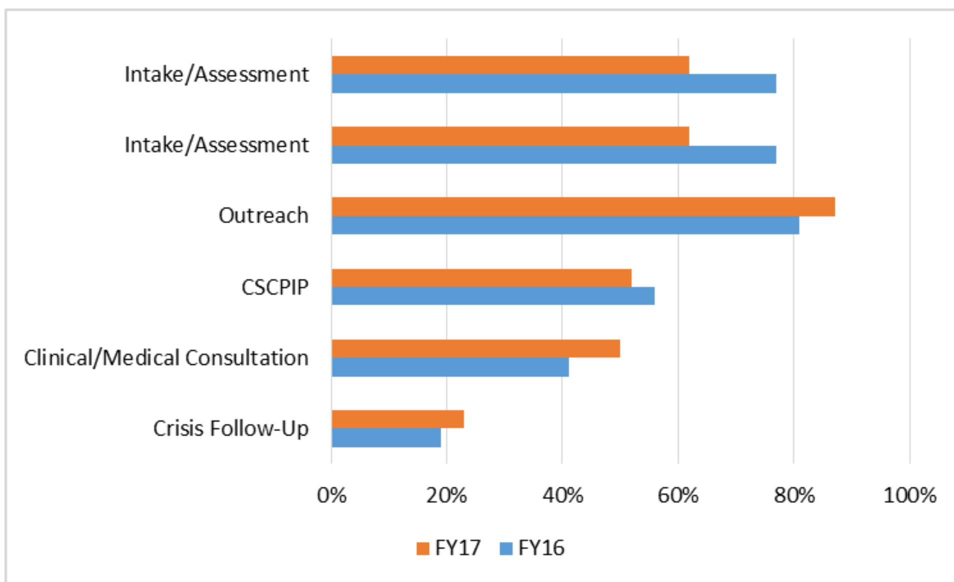



**Figure IV.C: Planned Service Utilization Trends (Percent of Children)**




## Summary

- Time spent on intake activities has gone down since last fiscal year, which is expected given the decrease in new enrollments.
- The documented time spent on CSCPIP planning appears low, at just under 60% of individuals enrolled in the year. Because each CSCPIP is required to be updated at least annually, this percentage should be much higher. This should be an area of focus in the coming year.

## START Intake and Assessment

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 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 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 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. While the RSQ has primarily been used as a clinical tool to ensure that interventions are addressing identified stressors, the National START Team is working to develop new ways of using and presenting this information to inform both clinical practice and as an outcome measurement.

The Family Experiences Interview Schedule (FEIS) is a semi-structured interview developed by Tessler & Gamache to help measure caregivers' perceived support from and attitudes towards the mental healthcare system. The FEIS was chosen since it directly aligns with and measures the primary goal of START: to improve access, appropriateness and accountability of the mental health service system. The FEIS is only administered when an individual resides at home with his/her family.

**Table IV.B: Percentage of active individuals who received assessments/tools**

| START Tools | FY16 | FY17 |
|---|---|---|
| *START Action Plan* | 97% | 95% |
| *Aberrant Behavior Checklist (ABC)* | 61% | 86% |
| *Recent Stressors Questionnaire (RSQ)* | 63% | 87% |
| *Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)* | 56% | 79% |
| *Comprehensive Service Evaluations CSEs Completed* | 3% | 3% |

## 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 ID. (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=178). Note that Region 3 does not have enough children enrolled with two ABC administrations to break out this analysis by age.

For those individuals receiving services with at least two administrations in SIRS (n=178), results show that average scores decreased in each subscale as shown in Table 14.

**Table IV.C: ABC Analysis**

| | | Mean Score | | | |
|---|---|---|---|---|---|
| **Region 3 (N=178)** | **Percent with Improvement** | **Initial** | **Most Recent** | **t Stat** | **P(T<=t) one-tail** |
| Hyperactivity/Noncompliance | 74% | 21.51 | 14.17 | 9.04 | 0.00 |
| Inappropriate Speech | 47% | 4.03 | 2.78 | 4.90 | 0.00 |
| Irritability/Agitation | 70% | 21.67 | 15.05 | 7.62 | 0.00 |
| Lethargy/Social Withdrawal | 59% | 11.65 | 9.02 | 3.88 | 0.00 |
| Stereotypic Behavior | 48% | 4.55 | 3.20 | 4.31 | 0.00 |

Alpha= 0.05

## Summary:

- ABC scores improved in all subscales during re-administration with the largest improvement being in the irritability/hyperactivity subscale. This is consistent with other research findings.
- The completion of CSCPIPs in FY2017 is 79%, which is an improvement of over 20% from FY2016. This still does not meet program certification requirements (completion rate of 85% is meeting minimum standards) at this time, so the program will continue to work on this into next year.
- The rate of completion for CSE's is well below what is expected of existing programs. CSEs are completed when it is clinically indicated to do so and on average, about 20% of all active cases require a CSE. This is the benchmark for certified programs and also established programs such as Region 3, which will be applying for certification status in the near future.

## Recommendations

- The Region 3 program should analyze how coordinators are entering time spent in crisis planning to understand why the documented time spent on these activities is lower than expected. A plan to improve this area of time tracking should be developed.
- Region 3 should also monitor and assure that crisis plans are being completed and entered into SIRS at a frequency that is in line with other established programs in the START network (85% completion rate)
- A plan to improve the completion of the CSE tool should be developed. This is a valuable resource for many teams and is being underutilized in Region 3 with only 3% of enrolled individuals receiving this service during the reporting period.

## Family Experiences Interview Schedule (FEIS)

FEIS assessments are conducted at intake and after 1 year of STRAT services on over 60 individuals living with their families and receiving START services in Region 3. These data were used as part of a larger study, "Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program." Results of this study are currently under review for publication and when published, will be available to stakeholders receiving this report. Additional FEIS outcomes will be analyzed and included in future annual reports.

## Recommendations

- The National START Team will work with Region 3 to develop some metrics utilizing FEIS data that can be used to evaluate the work of START in improving family perceptions of the mental health care their family members receive.

## 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

Region 3 START 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 17 (March 31, 2017). During the period of this report, Region 3 START responded to 483 crisis calls from 93 different individuals (29% of population). This is more than double the calls received in FY16 and a 10% increase in the percentage of individuals utilizing crisis services. Details for these calls are provided below.

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

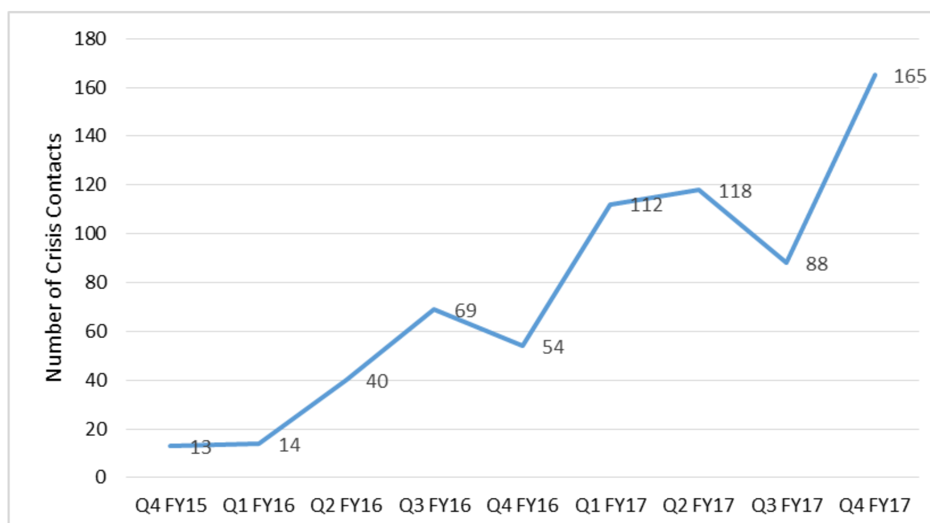


**Table IV.C: FY17 Crisis Contacts**

| Crisis Contacts | FY16 | FY17 |
|---|---|---|
| Total individuals | 56 | 93 |
| Total number of crisis contacts | 177 | 483 |
| Average number of contacts | 3.4 | 5.2 |
| Number of individuals with more than 1 Emergency/Crisis services | 43 | 55 |
| Percent of individuals with more than 1 Emergency/Crisis services | 77% | 59% |

**Table IV.D: Type of Crisis Response**

| | Adults | | Children | | Total: FY17 | |
|---|---|---|---|---|---|---|
| Type of Response | N | % | N | % | N | % |
| In-Person | 63 | 14% | 8 | 17% | 71 | 15% |
| Phone consultation only | 365 | 84% | 38 | 79% | 403 | 83% |
| Unreported | 7 | 2% | 2 | 4% | 9 | 2% |
| Total Contacts | **435** | **100%** | **48** | **100%** | **483** | **100%** |

**Table IV.E: Outcome of Crisis Contact**

| | Adults | | Children | | Total: FY17 | |
|---|---|---|---|---|---|---|
| **Outcome of crisis contact** | **N** | **%** | **N** | **%** | **N** | **%** |
| Community mental health in-patient unit admission | 8 | 2% | 2 | 4% | 10 | 2% |
| Crisis stabilization unit/bed | 2 | 0% | 1 | 2% | 3 | 1% |
| Detention/jail | 1 | 0% | | 0% | 1 | 0% |
| Emergency Department/CPEP | 28 | 6% | 4 | 8% | 32 | 7% |
| Maintain current setting | 357 | 82% | 34 | 71% | 391 | 81% |
| Medical Evaluation/Admission | 2 | 0% | 1 | 2% | 3 | 1% |
| Referral out for services | 9 | 2% | | 0% | 9 | 2% |
| State operated/private ICF/DD or other I/DD facility | 1 | 0% | | 0% | 1 | 0% |
| State psychiatric hospital admission | 1 | 0% | 1 | 2% | 2 | 0% |
| Unknown | 2 | 0% | | 0% | 2 | 0% |
| Unreported | 24 | 6% | 5 | 10% | 29 | 6% |
| **Total FY17 Crisis Contacts** | **435** | **100%** | **48** | **100%** | **483** | **100%** |

## Summary

- 93 individuals enrolled in services received crisis services from START in the last fiscal year amounting to nearly 500 contacts. More than half of the 93 individuals who received crisis services in the year had more than one contact.
- In over 80% of 483 calls received during the year, Region 3 START coordinators were able to provide emergency support and response that allowed the individual to either remain in or to return to his/her home.
- Data also reflects that the Region 3 program responded to a crisis call in-person less than 20% of the time. This is lower than what is expected for START programs.

## Recommendations

- The high rates of crisis calls for less than half of the individuals enrolled in services may mean that the START program is using their crisis line like a hotline or warmline. More systemic engagement with individuals' teams/supports is needed along with a closer analysis of the data to assure that contacts are coded correctly in the database.
- A plan needs to be developed in order to assure that the team leaders and coordinators have the skills and a clear understanding of START crisis contacts to assure that they are responding in person when necessary. Less than 20% of individuals who call the crisis line receive a face-to-face assessment. This may be due to ongoing limitations in face-to-face response after hours, which remains to be resolved at this time.

# Conclusions and Recommendations for FY18

## Conclusion

FY17 has been a year of positive change and progress for NYSTART Region 3. This past year has been marked with success at many levels. During this past year, NYSTART Region 3 has worked hard to provide greater outreach to community systems including residential providers, mental health agencies, families and first responders. This outreach includes not only the promotion of the START model but specific training to the community on the role of START. In fact, according to SIRS data during the past year the program has doubled the amount of outreach provided compared to last year. Region 3 continues to work to develop and update linkage agreements with mobile crisis programs, hospitals, residential providers and stakeholders.

NYSTART Region 3 has also developed relationships with local colleges to offer field placements to under-graduate students at each of the Region 3 hubs, which will begin to develop increased capacity and a solid infrastructure of trained professionals working in the field with individuals with IDD and complex behavioral health issues.

During this past year, NYSTART Region 3 has developed a certification study group to support coordinators working towards their certification. Because of these efforts, Region 3 has been able to train and successfully prepare eight coordinators for national coordinator certification. It is expected that at least as many coordinators to be certified during this upcoming year.

The program's data collection through the START Information Reporting System (SIRS) has improved this year. NYSTART Region 3 is either meeting or exceeded the data compliance elements for certified START programs. Concurrently Region 3 has also demonstrated improvements in the completion rates for both Cross Systems Crisis Prevention and Intervention Plans (CSCPIP's) and Comprehensive Service Evaluations (CSE's).

NYSTART Region 3 continues to work in partnership with State and regional OPWDD liaisons to develop in-home mobile and center-based resource center services. Renovations to the Resource Center are expected to be complete during the fall of 2017. The development of these therapeutic resources are needed and will further enhance services for individuals with IDD and complex behavioral health issues and will represent the full-array of START services for Region 3.

NYSTART Region 3 continues to work towards full compliance with START model fidelity with the goal of becoming a fully certified lifespan program. The program will continue to move forward through collaborative efforts with national, state and regional partners and ultimately strengthen systems of support for professionals, families and individuals in Region 3.

## Recommendations for Fiscal Year 2018

## Program Enrollment

- While the percentage of children enrolled in the Region 3 program remains consistent across years, it is unclear as to whether the caseload make up (80% adults and 20% children) mirrors what is seen in all Region 3 OPWDD services or if additional and continued strategic outreach, linkage and education to providers and stakeholders that traditionally serve children in the region is needed. The START program should also work with the OPWDD regional office to gain more insight into enrollment trend and determine whether there are untapped referral resources in the region.

## Characteristics of Persons Served

- Although the high percentage of both children and adults residing in supervised settings is a trend that has been identified since the inception of the program, it is important to continue to monitor and understand. A primary goal of START is to support individuals in their natural, family settings and therefore more outreach to families and service providers should be done in order to receive referrals prior to out of home placement whenever possible.
- One service that may promote the referral to START prior to out of home placement is In-home therapeutic supports. The Region 3 program does not yet offer this service but continues to work with OPWDD Regional and state offices to develop a plan to implement these services.

## Emergency Service Trends

- Outreach and connection to the children's service system and families to increase referrals and encourage referrals for children and families who are at risk for emergency services use.

## START Clinical Services

- Provide the Mental Health and IDD training to every emergency room and inpatient psychiatric unit in our region. We purchased several copies of the DM ID 2 manuals to share with settings we present to, in an effort to aid staff at those settings to feel more comfortable and knowledgeable when working with the dually diagnosed population.
- Modify the Mental Health and IDD training, which, at present, is tailored more toward mental health providers, by creating a similar training for IDD providers and one for direct support professionals.
- Utilize technologies available to us to reach a broader audience and expand the availability of START trainings to more providers. For example, we would like to offer our trainings via WebEx, which would allow flexibility for participants to view the trainings from their own computers/phones - in their offices, remotely, or in large group settings. This also will allow NYSTART staff an opportunity to provide more trainings to larger audiences without having to travel far distances to provide the trainings one at a time to our community partners.
- Partner with the Performing Partner System's throughout the region to assist in offering/providing the Mental Health and IDD training. Addressing the Medicaid population with behavioral health diagnoses is a key component of DSRIP, as it has been shown that this population has the majority of avoidable hospital use, not only because of the behavioral health diagnoses but also because of medical diagnoses that are not being well addressed in the current health care system in NYS. The MH/IDD training is in-line with DSRIP's mission in increasing the capacity of the workforce and decreasing emergency and inpatient hospital utilization.
- The Region 3 program should analyze how coordinators are entering time spent in crisis planning to understand why the documented time spent on these activities is lower than expected. A plan to improve this area of time tracking should be developed.
- Region 3 should also monitor and assure that crisis plans are being completed and entered into SIRS at a frequency that is in line with other established programs in the START network (85% completion rate)
- A plan to improve the completion of the CSE tool should be developed. This is a valuable resource for many teams and is being underutilized in Region 3 with only 3% of enrolled individuals receiving this service during the reporting period.

- The National START Team will work with Region 3 to develop some metrics utilizing FEIS data that can be used to evaluate the work of START in improving family perceptions of the mental health care their family members receive.

- The high rates of crisis calls for less than half of the individuals enrolled in services may mean that the START program is using their crisis line like a hotline or warmline. More systemic engagement with individuals' teams/supports is needed along with a closer analysis of the data to assure that contacts are coded correctly in the database.

- A plan needs to be developed in order to assure that the team leaders and coordinators have the skills and a clear understanding of START crisis contacts to assure that they are responding in person when necessary. Less than 20% of individuals who call the crisis line receive a face-to-face assessment. This may be due to ongoing limitations in face-to-face response after hours, which remains to be resolved at this time.