NC START

Systemic • Therapeutic • Assessment • Resources • Treatment

North Carolina START Program: Central Region

FY17 (July 2016 – June 2017)

Annual Report

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

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

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Executive Summary

Since 2008, NC START (Systemic, Therapeutic, Assessment, Resources, and Treatment) has been a part of the North Carolina system working to achieve its mission of creating a support network that will provide crisis prevention and intervention supports for individuals with IDD and behavioral health needs. NC START Central, in collaboration with NC START West and NC START East, has worked with state and regional partners to provide high fidelity START services to meet the needs of individuals with IDD and behavioral health needs within the changing system of support. This past year saw great growth in NC START Central services provided to children/youth and increased collaboration with the state and the LME/MCOs as a result of additional funding for NC START.

This past fiscal year, the NC START Central team added 4 START Coordinators to its already existing 9 Coordinator team, an additional Clinical Team Lead, and 2 Therapeutic Coaches. Some of these positions are funded by the state, while other positions are funded by Alliance Behavioral Health and Sandhills Center, providing the START program with an opportunity to support more children and families in the region. This expansion has also allowed NC START Central to increase its collaboration with providers who serve children and families such as Intensive In-Home Teams, Therapeutic Foster Care providers, multiple school systems, ABA therapists and children's MCO care coordinators.

During the current reporting period, 130 individuals were newly enrolled with NC START Central, and a total of 229 individuals were served. Of these 229 individuals, 147 of those were children. Approximately 50% of the children/youth served had a diagnosis of autism spectrum disorder. The percentage of enrolled individuals who live at home with family is 44% for adults and 73% for children. The percentage of children living in congregate care settings such as group homes or residential treatment facilities is larger than other START programs in the country, which points to a need for early outreach and engagement in services for children in the region. This is something NC START Central hopes to impact through collaboration with community providers, including advocacy groups and pediatric practices. To address some of the needs of families of children with IDD living at home, Therapeutic Coaching was provided. Coaching for children, along with the Resource Center services for adults, 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. In addition, there was improvement in key mental health clinical signs and symptoms that are often linked to emergency service use.

In collaboration with the National Center for Center for START Services (CSS) at the Institute on Disability, University of New Hampshire, NC START Central has maintained fidelity to the START model and was reviewed by CSS and maintained its National Certification status. An essential aspect of the model is collection of data. Through the START Information Reporting System, all elements of service delivery along with de-identified information about service users are entered into a database in order to evaluate NC START Central outcomes and compare those to state and national trends. The report to follow provides a detailed analysis of NC START Central for the 2017 fiscal year.

Contributors to this report and the information in it are:

Jillaine VanEssen Baker, MSW, LCSW, MTS, Director, NC START Central

NC START Central Program

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

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

Goals from 2016 Annual Report/Progress

1. Obtain full Certification for program (Lifespan).
    - *Granted full Certification for Lifespan services in June of 2017.*
2. Hire and cross-train for all positions needed for adult and children's program.
    - *Throughout FY2016 NC START Central continued to hire and train additional Child Coordinators. As of the end of FY2016, NC START Central hired a total of 9 Coordinators, 4 Team Leads, and 4 Coaches to implement Child Services.*
3. Prepare and obtain coordinator certification for all eligible Coordinators.
    - *Due to the constant hiring of additional Coordinators/Team Leads, this is ongoing. In FY2016, NC START Central certified 7 Coordinators. All other coordinators have dates in the coming year to be certified. In order to maintain national program certification at least 50% of eligible team members need to be certified at any given time. The NC Central program meets this standard.*
4. Seek linkages for children's services.
    - *Linkages to schools, providers, hospitals and crisis centers have been sought.*
    - *This fiscal year we were able to add a linkage agreement from one hospital, one day program, one community provider and one ICF.*
    - *This goal is on-going as we continue to seek partnerships, particularly in the school system.*
5. Expand training in the children's services arena.
    - *NC START Central completed multiple trainings in multiple areas of children's services including the school system, Murdoch Developmental Center, Intensive In-Home providers, Foster Care placements and Care Coordination.*
    - *START held its first Professional Learning Community (PLC) in March of 2017. With representation from each of our 3 MCOs (Cardinal, Alliance and Sandhills) and Central Regional Hospital, the PLC focused on Children with dual diagnoses. Two more PLCs will take place in fiscal year 2018.*
6. Implement START Therapeutic Coaching
    - *START Therapeutic Coaching officially began in March of 2017. Since its beginning, we have expanded to 4 Coaches and are offering coaching to all counties within our region.*
    - *Therapeutic Coaching was provided to 27 individuals this fiscal year. While this is lower than expected, we only had 2 coaches for almost 8 months of the fiscal year. Our goal is to serve more in the upcoming year.*
    - *Protocols around planned and emergency coaching were developed through the year and continue to be modified as the program develops.*
7. Decrease adult services waitlist.
    - *This goal is ongoing and significant updates will occur in this upcoming fiscal year. START's intent is to build system capacity and the ultimate goal is to decrease the wait time for START and other community services. Therefore, the program is diligently working to eliminate the waiting list for START services in the coming year.*

Findings

The following report provides an analysis of enrollment, demographic and service outcome data for the NC START Central program for fiscal year 2017 (July 1, 2016- June 30, 2017).

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

Section I: Program Enrollment

Data below reflect all individuals who were enrolled in NC START Central during FY17 (N=229). Individuals who declined services or were ineligible for START services are not included in this report. Past reports have considered children to be under age 18, but in conjunction with the settlement agreement that expanded START services to children, this report and all future reports will consider youth to be individuals under age 21. Due to this change in reporting, fiscal year comparisons are unavailable for this report but will be available in the future.

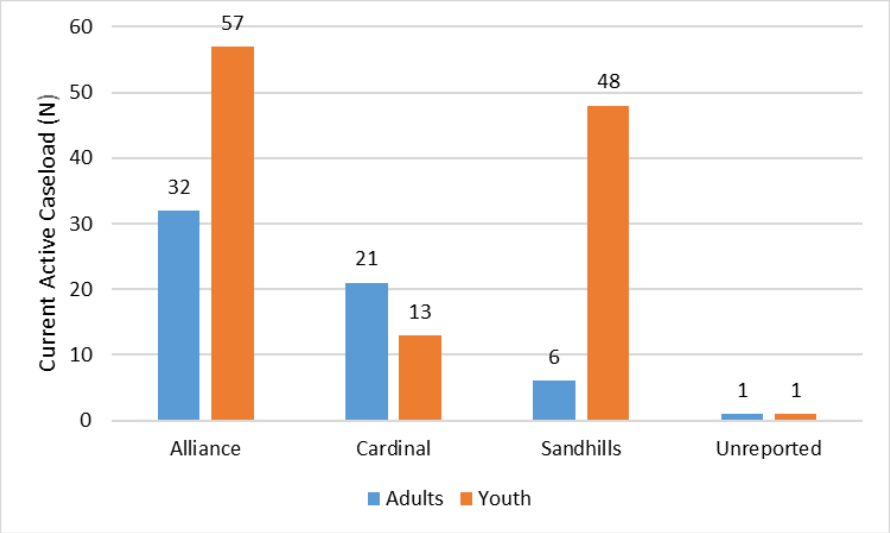
Table I.A: Enrollment Trends: Adults (21+ years old)

	FY17
Total Caseload at Beginning of Reporting Period	67
Individuals **Enrolled** During Reporting Period	15
Individuals **Inactivated** During Reporting Period	22
Total Caseload at End of Reporting Period	60
Individuals Served During Reporting Period	82
Percentage of Total Caseload	36%

Table I.B: Enrollment Trends: Youth (6 -20 years old)

	FY17
Total Caseload at Beginning of Reporting Period	32
Individuals **Enrolled** During Reporting Period	115
Individuals **Inactivated** During Reporting Period	28
Total Caseload at End of Reporting Period	119
Individuals Served During Reporting Period	147
Percentage of Total Caseload	64%

Figure I.A: Active individuals by MCO



Reasons for individuals becoming inactive

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) during FY17 was 20 months for adults, which falls just outside the National average of 12 – 18 months. For youth the average LOS was 6.5 months, but the majority were inactivated for reasons other than stable functioning. For those inactivated as stable, the LOS was 16 months, which is within the START guidelines.

Table I.C: Reasons for individuals becoming inactive in FY17

Variable	**Adults**	**Youth**
N	22	28
Reason for Inactivity (%)		
Stable functioning	68%	25%
No longer requesting services	9%	21%
Moved out of START region	18%	11%
Long-term hospitalization/DC placement	5%	32%
Inappropriate for services	0%	7%
Other (unable to contact)	0%	4%

Table I.D: Source of Enrollment to START

Variable	**Adults**	**Youth**
N	15	115
Source of Enrollment (%)		
Service Coordinator	47%	93%
Community psychiatric inpatient	7%	0%
Residential/day provider	27%	0%
Friend	0%	1%
Hospital emergency department	0%	1%
Other	20%	0%
Unreported	0%	5%

Table I.E: Reasons for enrollment

Variable	Adults	Youth
N	15	115
Most Common Reasons for Enrollment (%)		
Aggression	93%	95%
Family Needs Assistance	7%	74%
Risk of losing placement	20%	32%
Mental Health Symptoms	80%	56%
Suicidality	7%	24%
Self-Injurious Behavior	20%	39%
Sexualized behavior	20%	26%
Leaving unexpectedly	80%	47%
Transition from hospital	7%	26%
Decreased ability to function	0%	17%

Summary

- The adult caseload is significantly low at 87 individuals actively enrolled at the end of the reporting period. Some of this is due to the change in age classification as part of the NC settlement agreement. However, this does not completely account for the caseload numbers and caseload numbers will increase in the next reporting period.
- The large increase in the child caseload from 32 to 147 in the reporting period is due to the increase in staffing and capacity to enroll more children. At the beginning of fiscal year 2017, NC START Central had 2 fully trained Child Coordinators and 3 coordinators in training at the conclusion of FY2016. At the end of this reporting period, there were 9 Child Coordinators allowing for a higher caseload of 147.
- It is significant that 32% of the child caseload went inactive due to long-term hospitalization within such a short period of time with START services. As linkages are developed and services are more clearly defined and integrated into the community safety net, NC START Central hopes to enroll individuals and be able to assist with stabilization before long term hospitalization is explored and/or requested.
- Ninety-three percent of referrals for children came from MCOs, which is significantly more than adults (47% of referrals). This is this result of protocols being put in place in which the MCOs will monitor and submit referrals to the START program. This has provided for the development of strong working relationships with MCO care coordinators and timely enrollment of children in need of services. The result is that our collaborative partnership not only begins earlier in the process, but has become stronger.

Goals

- Increase adult caseload and ensure child caseloads are at recommended capacity. Use START plans to align caseload intensity with recommended caseload size per Center for START Services.
- Explore the cases that went inactive quickly due to long term hospitalization. Ensure that they were or will be reactivated upon discharge. In addition, ensure that the START team stays involved while individuals are hospitalized to ensure a positive and successful discharge and transition home.
- Evaluate and expand current linkages targeting community and state hospitals that are likely to admit children to their units in order to coordinate discharge planning for children admitted. In addition, the program will evaluate linkage practices with community providers to assure that hospital diversion occurs whenever possible. Addressing waiting list issues within the program will also assist with this.

Section II: Characteristics of Persons Served

Demographics

Section II of this report provides demographic and diagnostic trend data for all individuals served by NC START (N=229) during FY17 (July 1, 2016-June 30, 2017). There are no significant differences in the demographics of active individuals in FY17 compared to previous fiscal years. When relevant, the NC START population is compared to populations from other START programs nationally.

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

	Adults (21+)		Youth (6-20)	
Variable	**FY17: NC Central**	**FY17: Other START Programs**	**FY17: NC central**	**FY17: Other START Programs**
N	82	1705	147	809
Age (Mean)	**29**	35	15	16
Gender (% male)	56%	60%	77%	76%
Level of Intellectual Disability (%)				
No ID/Borderline	2%	8%	16%	14%
Mild	48%	47%	37%	38%
Moderate	35%	26%	19%	26%
Severe-Profound	1%	9%	7%	7%
Level Unspecified	9%	6%	18%	13%
Missing	5%	3%	3%	3%
Living Situation (%)				
Family	44%	35%	73%	83%
Enhanced family care	11%	9%	**4%**	2%
Group Home and Community ICF/DD	32%	30%	**12%**	6%
Independent/Supervised	6%	13%	0%	2%
Psych. Hospital/IDD Center	4%	3%	**5%**	2%
Other (Jail, Homeless, "Other")	4%	7%	3%	3%
Missing	0%	3%	3%	1%
Funding Source (%)				
IDD Waiver	45%	49%	22%	40%
Medicaid	52%	37%	63%	45%
Medicare	0%	1%	0%	0%
Private Insurance	1%	2%	12%	4%
State funds	1%	2%	1%	2%
Missing	0%	9%	3%	9%

Summary

- When compared to other START programs throughout the county, the demographics of adults served by NC START Central are quite similar. One difference is the mean age of adults enrolled in NC START Central (mean age 29) compared to other START programs (mean age 35). This points to a need to focus on supports for transitional age youth.
- More children in NC START Central reside in therapeutic foster care, group living environments and state facilities than other START programs nationally. This is a trend that requires continued monitoring and discussion with The Division of MHDDSAS, Child Protective Services, the state and other stakeholders.

Goals

- Explore training possibilities to IDD Centers and psychiatric hospitals around treatment of individuals with IDD to ensure transition planning is thorough, helpful and takes into account the strengths of the individual, increasing the likelihood of support that creates success.
- Create more formal linkages with those screening the child referrals to discuss early enrollment for individuals prior to IDD Centers and hospitals. The goal is to prevent unnecessary stays in IDD Centers and hospitals.
- Continue to monitor living arrangements for children enrolled in START and regularly discuss strategies to address with START Advisory Board.

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 influence 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 resulted in an important update to how mental health conditions are categorized and reported in SIRS. Because of this recent update, MH condition trend data is not available for this reporting period. However, the reporting of identified mental health diagnoses is consistent with last fiscal year. In addition, a comparison of the frequency of diagnostic categories between NC START and other START programs is available.

It is also important to note that 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 (21+)		**Youth (6-20)**	
Variable	**FY17: NC Central**	**FY17: Other START Programs**	**FY17: NC Central**	**FY17: Other START Programs**
N	82	1705	147	809
Mental Health Conditions (%)				
At least 1 diagnosis	79%	84%	83%	78%
Mean Diagnoses	1.8	2.0	2.2	2.1

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

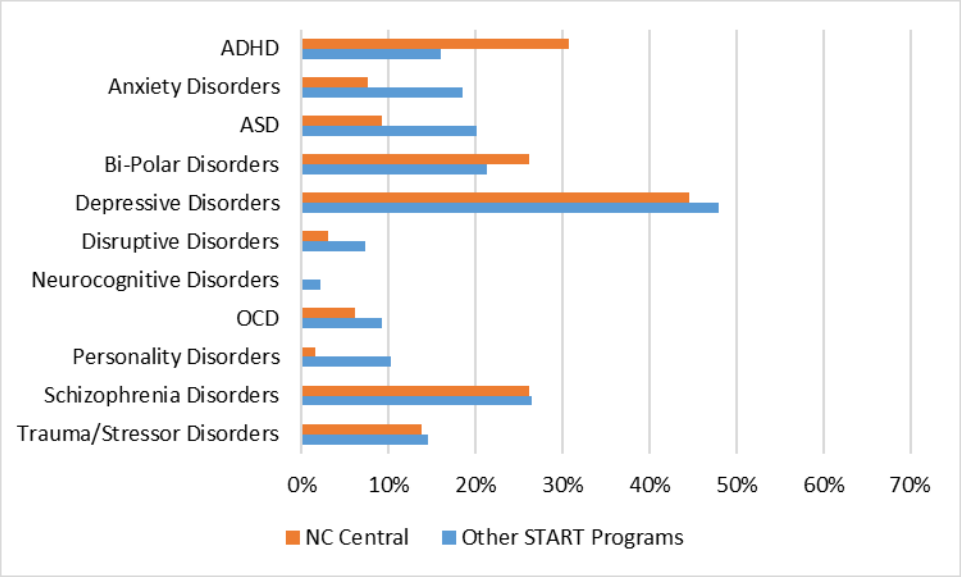
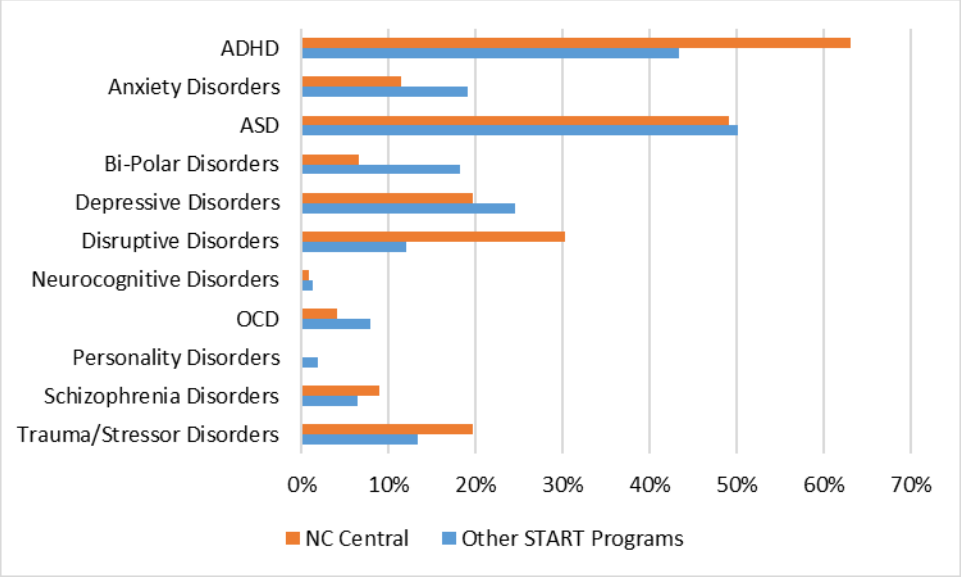


Figure II.B: Frequency of most common mental health conditions for enrolled youth



Summary

- The diagnosis of ADHD is significantly higher in NC Central than other START programs for both adults and children.

  The diagnosis Disruptive Disorders is significantly higher in the children served in NC START Central when compared to other START programs. One factor that may result in a high percentage of youth diagnosed with disruptive disorder may be due to a need to increase knowledge, and improve assessment practices associated with trauma and IDD.

Goals

- Provide additional training for the START team by the Clinical Director and Medical Director specifically around differential diagnosis related to ASD, ADHD and Disruptive Disorders as these are the most common mental health diagnoses occurring for the referrals.
- Increase outreach and training around trauma in individuals, specifically around how trauma is expressed in individuals with IDD and how this may resemble symptoms associated with disruptive disorder diagnoses.

Chronic Health Conditions

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

Figure II.C: Chronic health conditions

	Adults (21+)		Youth (6-20)	
Variable	**FY17: NC Central**	**FY17: Other START Programs**	**FY17: NC Central**	**FY17: Other START Programs**
N	82	1705	147	809
Chronic Medical Conditions (%)				
At least 1 diagnosis	50%	66%	44%	51%
Mean Diagnoses	2.1	2.1	1.6	1.6

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

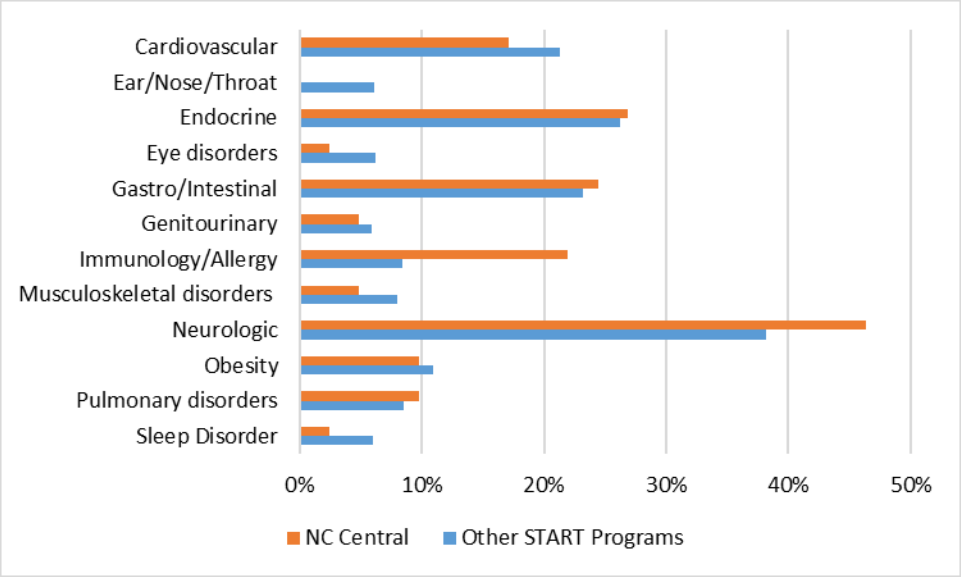
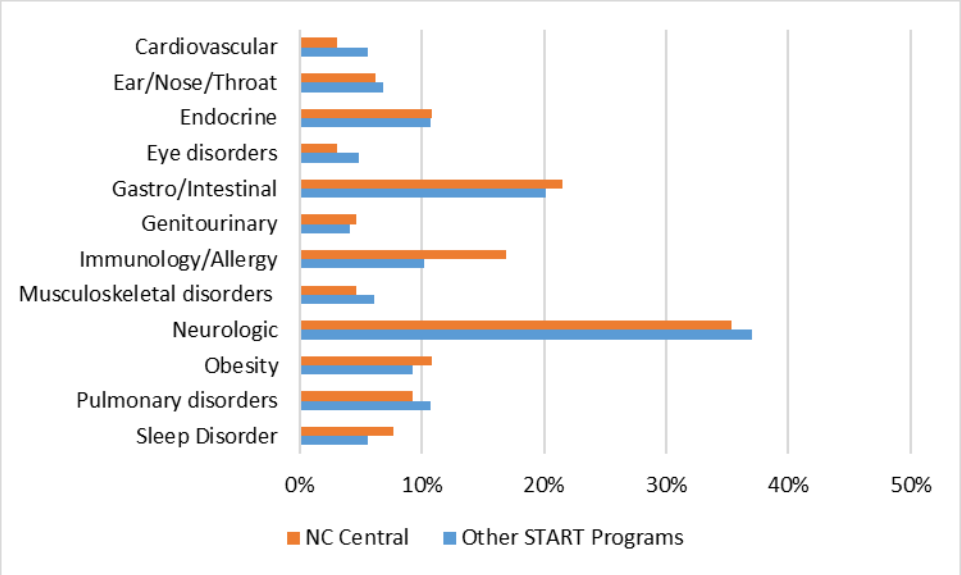


Figure II.D: Frequency of most common chronic medical conditions for enrolled youth



Summary

- The mean number for medical conditions in both adults and children match those of other START programs, 2.1 and 1.6, respectively.
- The most common medical conditions reported are neurological, gastro/intestinal and endocrine. This may be related to the high percentage of individuals with ASD since gastrointestinal issues and neurologic conditions are frequent in this population.
- Adults report a higher rate of medical conditions. This may be related to the high rate of medication prescribed to those with IDD and complex behavioral health needs. Adults have been on the medication for more years than children.

Goals

- Ensure adequate consultation for gastrointestinal, endocrine and neurologic conditions. Work with START Medical Director and RN to identify system gaps and strategies to address gaps.
- Increase trainings to the system around medical conditions and associated vulnerabilities for individuals with IDD. Further education and awareness of medical conditions and their possible connection to behavioral health challenges will benefit individuals, their system and health providers.
- Improve partnerships with pediatricians and primary care doctors to discuss medication side effects as these side effects can have an impact on behavioral health challenges as well as increase the need for more medications.

Section III: Emergency Service Trends

A number of NC START 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 (21+)	Youth (6-20)
N	82	147
Psychiatric Hospitalizations		
Prior to enrollment, N (%)	48%	48%
Mean (range)	1.9 (1-7)	2.1 (1-7)
Percent with Multiple Admissions	41%	50%
During START, N (%)	**22%**	**9%**
Mean (range)	1.7 (1-5)	1.2 (1-2)
Percent with Multiple Admissions	**28%**	**23%**
Emergency Department Visits		
Prior to enrollment, N (%)	71%	50%
Mean (range)	3.4 (1-18)	2.7 (1-12)
Percent with Multiple Visits	68%	47%
During START, N (%)	**37%**	**13%**
Mean (range)	2.3 (1-1)	1.3 (1-3)
Percent with Multiple Visits	43%	32%

Summary

- Preliminary findings show a decrease in psychiatric hospitalization rates and emergency department utilization for both children and adults during the enrollment with start. This suggests that involvement with START creates alternatives to emergency department use when an individual is experiencing an acute crisis.
- While there is a reduction in ED use and psychiatric hospitalizations, there continues to be a high rate of individuals with multiple visits as well as long term hospitalizations for children.

Goals

- The over-reliance on the ED continues to be a trend in the system. NC START Central will continue to develop targeted strategies including outreach, training, and refinement of the cross system crisis plan to decrease this over-reliance. In addition, the program will diligently work to eliminate the waiting list for START services to also assist in decreasing the use of the ED.
- Outreach and linkages to both EDs and psychiatric hospitals must continue. Training and collaboration regarding admission, treatment and discharge could decrease an individual's future use of the emergency service.

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): 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, outreach, clinical and medical consultation, and cross systems crisis prevention and intervention planning; 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 NC START Central 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 NC Central team has engaged the community to provide training and education around the unique needs of individuals with IDD and co-occurring MH conditions and continue 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	92	214
Community-based training	7	12
Host Advisory Council Meeting	5	2
Provided training to day provider	2	0
Provided training to emergency services	5	11
Provided training to family	1	5
Provided training to other	2	7
Provided training to school	0	3
Provided training to physician/medical personnel	1	1
Provided training to residential provider	1	3
Provided training to state facilities (state hospitals, developmental centers)	7	0
Provided training to therapist/mental health providers	9	6
Time spent on affiliation and linkage agreements	1	1
Transition Support/Planning-Developmental Center	1	7
Transition Support/Planning-Psychiatric Hospital	3	0
Total Outreach Episodes	137	272
Linkage/Collaboration Agreements	**12**	**12**
Clinical Education Team (CET)	**4**	**5**

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

- Executive Functioning in People with IDD
- The Original Dual Diagnoses
- Child START Services
- Intro to NC START
- Autism and Behavioral Challenges
- Autism Spectrum Disorder
- MH/IDD
    - Mental Health providers
    - Central Regional Hospital Social Workers
- Positive Psychology
- Positive Support strategies for IDD
- Trauma Informed Approaches/Care
- IDD for Crisis Intervention Team in Emergency Services

National START Practice Groups

As part of the START model and the national START Professional Learning Community, NC START 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

- Community Outreach and trainings in FY2017 more than doubled from FY2016.
- We had the same amount of Linkage Agreements this year as that of 2016.
- We had a low amount of CETs this past fiscal year, only doing one more than the previous year.
- NC START Central hosted its first Professional Learning Community this year, graduating 100% of its participants.
- NC START Central has participants in each one of the National Practice Groups above. NC START Central was able to send over 11 START members to the START National Training Institute in New York this past May. This group included leadership, coordinators, Resource Center counselors and START Therapeutic coaches.

Goals

- NC START Central will increase the amount of CETs provided to the community. Regular CETs are required to maintain program certification. In addition, CETs provide education and collaboration opportunities for stakeholders that are needed and important and a forum to discuss complex issues and potential strategies and remedies.
- The program will review current linkage agreements and develop a plan to update and/or develop new agreements with stakeholders within the region. With the very high number of enrollments for children in the region, additional linkage development and outreach may be needed to ensure positive collaborations with providers who primarily serve children.
- NC START will host 2 additional PLCs this upcoming year, with invitations to MCOs, the Division of State Operated Services, DHHS, Murdoch and Central Regional Hospital.

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.

- *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 implementing 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 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 NC START during the FY, while 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 stage 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

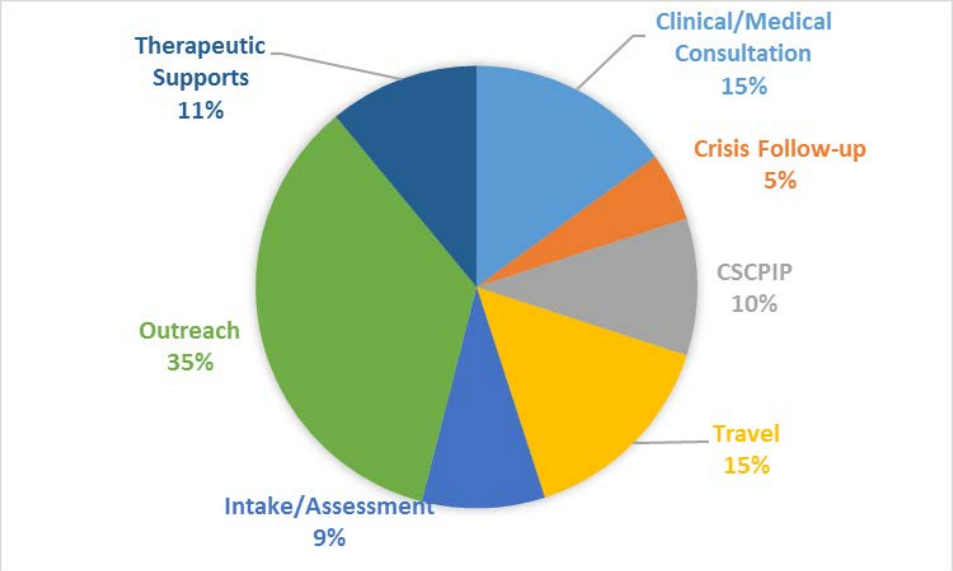


Figure IV.B: Planned Service Utilization Trends (Percent of Adults)

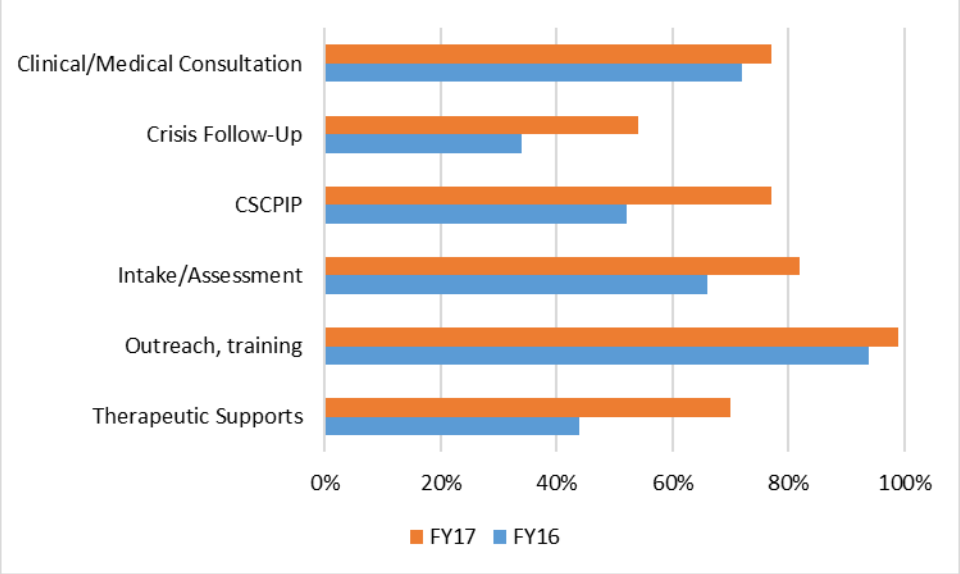
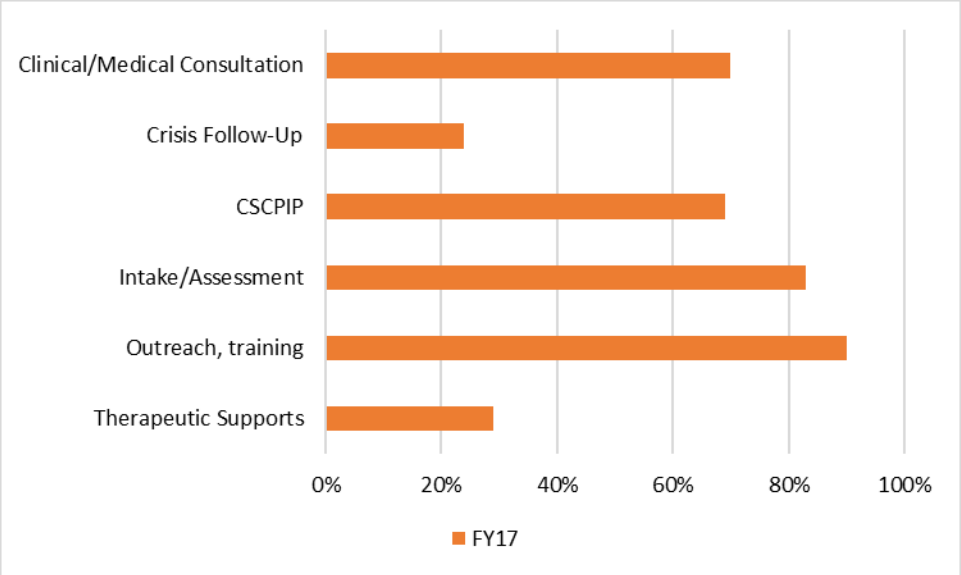


Figure IV.C: Planned Service Utilization (Percent of Youth)



Summary

- There was an increase in all planned, secondary service categories for adults this fiscal year compared to last. Due to this being the first year for child services, FY16 data is not available.
- Almost 100% of adults and 90% of children received outreach and/or training from the NC START Central team.
- Almost 80% of individuals received extra Clinical/Medical Consultation from our Medical Director, Clinical Director or RN.
- While the data on the services received by individuals shows a reasonable amount of crisis follow up, the first figure shows that only 4% of the services provided were crisis follow up. While this could be due to crisis services only being a small percentage of services given when compared to all the other services provided, it is important to ensure that the follow up post a crisis is not only completed, but documented appropriately, which includes an update to the Cross Systems Crisis Prevention and Intervention Plan (CSCPIP).
- Cross Systems Crisis Prevention and Intervention Planning for individuals is about 77% for adults and 70% for children. Because it is required that each individual not only receives a CSCPIP, but also receives updates annually, at minimum, this number should be at 100%. In addition, CSCPIP services should account for more than 10% of all Primary Services.

Goals

- Review protocols with the START team leads to ensure that each individual and system is not only given a CSCPIP but also receives regular training and updates as well as given multiple opportunity for feedback and collaboration regarding the CSCPIP.
- Ensure that proper follow up post crises are completed and documented accordingly, including an update to the CSCPIP. Ensure that this follow up is a part of each morning's triage call.

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), Family Experience Interview Schedule (FEIS), 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. 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.

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

START Tools	FY16	FY17
START Action Plan	85%	98%
Aberrant Behavior Checklist (ABC)	97%	99%
Recent Stressors Questionnaire (RSQ)	87%	98%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	93%	92%

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 at least 6 months of START service with at least two ABC scores were included (Adults N=70) (Children N=55).

For those individuals receiving services with at least two administrations in SIRS, results show that average scores decreased in each subscale as shown in the tables below.

Table IV.C: ABC Analysis: Adults

		Mean Score			
NC Central: Adults (N=70)	Percent with Improvement	Initial	Most Recent	t Stat	P(T<=t) one-tail
Hyperactivity/Noncompliance	67%	18.37	13.76	3.47	0.00
Inappropriate Speech	51%	3.21	2.99	.56	NS
Irritability/Agitation	74%	20.23	14.06	4.45	0.00
Lethargy/Social Withdrawal	49%	9.20	8.81	.38	NS
Stereotypic Behavior	49%	3.07	2.43	1.42	NS

Alpha= 0.05

Table 1V.D: ABC Analysis: Youth

NC Central: Youth (N=55)	Percent with Improvement	Mean Score		t Stat	P(T<=t) one-tail
		Initial	Most Recent		
Hyperactivity/Noncompliance	65%	27.91	21.36	3.58	0.00
Inappropriate Speech	38%	4.45	3.98	.79	NS
Irritability/Agitation	71%	25.82	19.33	4.25	0.00
Lethargy/Social Withdrawal	56%	13.58	11.13	2.01	0.02
Stereotypic Behavior	35%	6.35	5.95	.47	NS

Alpha= 0.05

Summary

- ABC scores improved in all subscales during re-administration with statistically significant improvements in hyperactivity/noncompliance, irritability/agitation and lethargy/social withdrawal. This is consistent with other START research findings.
- There has been an increase in completion for all START required assessments during this reporting period.
- Even though 92% of all active cases currently have a crisis plan in place, about 73% of individuals received crisis planning throughout the year. This may mean that plans are not being updated as needed/required, since all CSCPIPs should be updated at least one time annually and following a crisis contact.

Goals

- NC START Central will analyze how coordinators are entering time spent in crisis planning and other coordination activities as crisis planning time spent is lower than expected. A plan to improve this area of time tracking will be developed.
- The team will improve monitoring strategies to assure that crisis plans are being updated annually and after a crisis contact.

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

NC START Central coordinators provide crisis response for individuals enrolled in their program. The following chart reflects the number of documented acute crisis calls received by the program in FY 16 and FY17. Details for these calls are provided below.

Table IV.E: FY17 Crisis Contacts

	FY16	FY17	
Crisis Contacts	**FY16**	**Adults (21+)**	**Youth (6-20)**
Total individuals	67	**46**	42
Total number of crisis contacts	276	**298**	175
Average number of contacts	4.12	6.5	4.2
Number of individuals with more than 1 Emergency/Crisis services	43	33	24
Percent of individuals with more than 1 Emergency/Crisis services	64%	72%	57%

Table IV.F: Type of Crisis Response

	FY16		FY17	
Type of Response	N	%	N	%
In-Person	73	26.45%	100	21%
Phone consultation only	198	71.74%	**366**	**77%**
Unreported	5	2%	7	1%
Total Contacts	**276**	**100%**	**473**	**100%**

Table IV.G: Outcome of Crisis Contact

	FY16		FY17	
Outcome of crisis contact	**N**	**%**	**N**	**%**
Maintain current setting	226	82%	393	83%
Psychiatric hospital admission	3	1%	6	1%
Emergency Department Hold	14	5%	29	6%
Emergency Department	2	1%		
Referral out for services	2	1%	2	0%
Crisis Stabilization	4	2%	8	2%
Medical Evaluation/Admission	2	1%	0	0%
START Emergency RC admission	13	5%	24	5%
START Planned RC stay scheduled/In-home scheduled	6	2%	3	0%
Other	2	1%	2	0%
Unreported	2	1%	6	1%
Total Crisis Contacts	**276**	**100%**	**473**	**100%**

Table IV.H: Reason for Emergency Department Hold

Reason for ED Hold	FY16 (N)	FY17 (N)
Evaluation	3	9
No hospital beds available	3	3
No placement available	8	15
Other	0	2
Total	**14**	**29**

Summary

- There were 473 crisis events this fiscal year. While NC START Central increased people served this fiscal year, this is still a high number. Data also reflects that NC START Central responded to a crisis calls in-person about 21% of the time. This is lower than expected for START programs.
- 88 individuals enrolled in services received crisis services from START in the last fiscal year amounting to over 473 contacts. More than 64% who received crisis services in the year had more than one contact. Of the 88 individuals who received more than 1 contact, 9 individuals made up a large portion of these calls (15 or more calls/individual). This small number of individuals have used our crisis line as a warm line due to system gaps including minimal staffing, a limited number of therapists available in the community, and lack of natural supports. We are working on these gaps, with a focus on developing more natural supports and providing training to community therapists, and evidence of this will be seen in the coming year. The goal of START crisis response is to decrease recidivism, therefore this will be a goal in the upcoming year.
- In 88% of the 473 calls received, NC START Central coordinators were able to provide emergency support and response that allowed the individual to remain in their current setting or be admitted to the Resource Center for an emergency stay. This assisted in avoiding a higher level of care for these individuals such as an emergency department, walk in crisis facility or an in-patient hospitalization

Goals

- 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 to triage calls in a more effective way will be created so that the team is able to decipher a crisis call from a call that assists an individual or system in a non-crisis fashion.
- Develop a plan and/or training 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. This will include trainings around responses to individuals as well as team's members as START is a system approach and responds to the crises of the whole team. Only 25% of individuals who call the crisis line receive a face-to-face assessment.

Section V: START Therapeutic Resource Center Services

Table V.A: Planned Resource Center Stays

Planned Resource Center Stays	FY16	FY17
Number of individuals	56	44
Total number of stays	144	115
Range of days	1 to 21	2 to 11
Avg Length of Stay (Days)	4	4
Total time spent in resource center (in days)	602	501
Number of individuals with more than 1 Resource Center - Planned	38	34
Percent of individuals with more than 1 Resource Center - Planned	68%	77%
Occupancy Rate (2 beds X 365 days): 730 days	83%	68%

Table V.B: Emergency Resource Center Stays

Emergency Resource Center Stays	FY16	FY17
Number of individuals	26	21
Total number of stays	28	28
Range of days	4 to 35	3 to 30
Avg Length of Stay (Days)	22	16
Total time spent in resource center (in days)	588	590
Number of individuals with more than 1 Resource Center - Emergency	2	3
Percent of individuals with more than 1 Resource Center - Emergency	8%	14%
Occupancy Rate (2 beds X 365 days): 730 days	81%	81%

Therapeutic Coaching	FY17
Number of individuals	27
Total number of hours provided	1271
Avg hours/individual	47

Summary

- There was a decrease in Planned Resource Center Services this fiscal year. This can be seen not only in the decreased occupancy rate, but also in the number of individuals admitted into the Center this fiscal year. One possible reason for this could be an overall lower caseload for adults this year than in FY2016. Another reason could be multiple cancellations close to the day of admission. The team has discussed this and hypothesized that cancellations may occur due to scheduling stays quite far in advance.
- This includes both emergent and planned. Will include separation in next year's report.

- The occupancy rate of the Emergency Resource Center stayed about the same, at 81%. While recidivism rates for emergency admissions is still in line with START fidelity (14%), it is double the rate from last fiscal year. This will be monitored in the coming reporting period.
- The average length of emergency stays decreased from 22 days to 16. There may be a connection between the shorter average emergency stay and the increase in recidivism rates. This should be closely monitored to assure that thorough assessment, outreach, training and discharge planning is done.
- NC START Central supported 27 individuals through Therapeutic coaching, resulting in 1,271 hours of services provided. For 7 months of FY2017, START Central had 2 coaches providing services. The last 5 months of the year, 4 coaches provided services. This was the first year that coaching was provided all 12 months. NC START Central is part of a Therapeutic Coaching work group enhancing resources regarding methods and requirements in the home. Through this work group and discussions with other programs regarding their data, NC START Central will know further how this data compares to National Data.

Goals

- Examine protocol for planned Center admissions, ensuring that proper reminders and thorough planning is done on the part of START to decrease cancellations.
- An increase of enrollees over the age of 18 will allow for more individuals to have access to the therapeutic benefits of a planned Resource Center stay.
- Increase the amount of individuals served and hours provided through Therapeutic Coaching. As the program works with the National Team to develop more standards and requirements, NC START Central will adjust our documentation patterns and outcome measures.
- The Resource Center Director, along with the Clinical Director and Regional Director will review each emergency stay in a more critical way to ensure the length of stay is clinically appropriate, therefore, reducing the recidivism rate in emergency stays.

Conclusions and Goals for FY18

Conclusion

NC START Central experienced significant change and growth during this reporting period, adding several more coordinators throughout the year, an additional team lead position and two additional coaches to the START Therapeutic Coaching. There continues to be positive trends in reducing the use of emergency services and reduction of ABC scores, suggesting that START's involvement is positive and plays a significant role in the stabilization of individuals and the systems that support them. The Coordinators have worked diligently with individuals and families to provide education, training, consultation, assessments and crisis intervention

While NC START Central has had positive outcomes, there is room for improvement. Some of these areas include, increasing caseload sizes, ensuring crisis follow up is consistent and documented, updating crisis plans post crisis event and using our crisis line for situations which require an immediate response from the person on call. In addition, NC START Central must continue to link with stakeholders as our services have more than tripled in the past 2 years. There should be some emphasis on linkages within child services as these services are still new to NC START Central and well as increasing our training and education, specifically CETs.

NC START Central is committed to providing positive, solutions-focused START Services in the Central Region of North Carolina and proud to be a part of the START Network. NC START Central continues to grow and mature as a START team and was actively engaged in a solution-focused approach to the challenges presented during the past year. The coming year, NC START Central commits to effectively implement the START model, ensuring the continuation of its National START Certification.

Goals for Fiscal Year 2018

Program Enrollment

- Increase adult caseload and ensure child caseloads are at recommended capacity. Use START plans to align caseload intensity with recommended caseload size per Center for START Services.
- Explore the cases that went inactive quickly due to long term hospitalization. Ensure that they were or will be reactivated upon discharge. In addition, ensure that the START team stays involved while individuals are hospitalized to ensure a positive and successful discharge and transition home.
- Evaluate and expand current linkages targeting community and state hospitals that are likely to admit children to their units in order to coordinate discharge planning for children admitted. In addition, the program will evaluate linkage practices with community providers to assure that hospital diversion occurs whenever possible. Addressing waiting list issues within the program will also assist with this.

Characteristics of Persons Served

- Explore training possibilities to IDD Centers and psychiatric hospitals around treatment of individuals with IDD to ensure transition planning is thorough, helpful and takes into account the strengths of the individual, increasing the likelihood of support that creates success.
- Create more formal linkages with those screening the child referrals to discuss early enrollment for individuals prior to IDD Centers and hospitals. The goal is to prevent unnecessary stays in IDD Centers and hospitals.

- Continue to monitor living arrangements for children enrolled in START and regularly discuss strategies to address with START Advisory Board.
- Provide additional training for the START team by the Clinical Director and Medical Director specifically around differential diagnosis related to ASD, ADHD and Disruptive Disorders as these are the most common mental health diagnoses occurring for the referrals.
- Increase outreach and training around trauma in individuals, specifically around how trauma is expressed in individuals with IDD and how this may resemble symptoms associated with disruptive disorder diagnoses.
- Ensure adequate consultation for gastrointestinal, endocrine and neurologic conditions. Work with START Medical Director and RN to identify system gaps and strategies to address gaps.
- Increase trainings to the system around medical conditions and associated vulnerabilities for individuals with IDD. Further education and awareness of medical conditions and their possible connection to behavioral health challenges will benefit individuals, their system and providers.
- Improve partnerships with pediatricians and primary care doctors to discuss medication side effects as these side effects can have an impact on behavioral health challenges as well as increase the need for more medications.

Emergency Service Trends

- The over-reliance on the ED continues to be a trend in the system. NC START Central will continue to develop targeted strategies including outreach, training, and refinement of the cross system crisis plan to decrease this over-reliance.
- Outreach and linkages to both EDs and psychiatric hospitals must continue. Training and collaboration regarding admission, treatment and discharge could decrease an individual's future use of the emergency service.

START Clinical Services

- NC START Central will increase the amount of CETs provided to the community. Regular CETs are required to maintain program certification. In addition, CETs provide education and collaboration opportunities for stakeholders that are needed and important and a forum to discuss complex issues and potential strategies and remedies.
- The program will review current linkage agreements and develop a plan to update and/or develop new agreements with stakeholders within the region. With the very high number of enrollments for children in the region, additional linkage development and outreach may be needed to ensure positive collaborations with providers who primarily serve children.
- NC START will host 2 additional PLCs this upcoming year, with invitations to MCOs, the Division of State Operated Services, DHHS, Murdoch and Central Regional Hospital.
- Review protocols with the START team leads to ensure that each individual and system is not only given a CSCPIP but also receives regular training and updates as well as given multiple opportunity for feedback and collaboration regarding the CSCPIP.
- Ensure that proper follow up post crises are completed and documented accordingly, including an update to the CSCPIP. Ensure that this follow up is a part of each morning's triage call.
- NC START Central will analyze how coordinators are entering time spent in crisis planning and other coordination activities as crisis planning time spent is lower than expected. A plan to improve this area of time tracking will be developed.

- The team will improve monitoring strategies to assure that crisis plans are being updated annually and after a crisis contact.
- 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 to triage calls in a more effective way will be created so that the team is able to decipher a crisis call from a call that assists an individual or system in a non-crisis fashion.
- Develop a plan and/or training 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. This will include trainings around responses to individuals as well as team members as START is a system approach and responds to the crises of the whole team. Only 25% of individuals who call the crisis line receive a face-to-face assessment.

START Therapeutic Resource Center Services

- Examine protocol for planned Center admissions, ensuring that proper reminders and thorough planning is done on the part of START to decrease cancellations.
- An increase in enrollees over the age of 18 will allow for more individuals to have access to the therapeutic benefits of a planned Resource Center.
- Increase the amount of individuals served and hours provided through Therapeutic Coaching. As the program works with the National Team to develop more standards and requirements, NC START Central will adjust our documentation patterns and outcome measures.
- The Resource Center Director, along with the Clinical Director and Regional Director will review each emergency stay in a more critical way to ensure the length of stay is clinically appropriate, therefore, reducing the recidivism rate in emergency stays.