

NC START

Systemic • Therapeutic • Assessment • Resources • Treatment



North Carolina START Program: East Region

FY17 (July 2016 – June 2017)

Annual Report

Lisa Wolfe, MSW, LCSWA; Priscila Norris, MS, MSW, LCSW, Laurie Charlot, LCSW, PhD

NC START East RHA Health Services
1917 Trent Blvd, New Bern, North Carolina 28560
(252) 571-9039

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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.

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

Executive Summary

START (an acronym for Systematic, Therapeutic, Assessment, Resources, and Treatment) promotes a comprehensive system of care to optimize community living for individuals with intellectual/developmental disabilities (IDD) and mental health needs. The underlying philosophy of START is that services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions. In order for this to occur, collaboration between service providers and with service users is needed. The NC START project operates in association with the Center for START Services, a program of the University of New Hampshire Institute on Disability/University Center for Excellence in Disability. START has been recognized by the U.S. Surgeon General as a model program for supporting individuals with IDD and mental health/behavioral health needs and by the National Academy of Medicine as a best practice.

The START model requires certain clinical and therapeutic support team members to achieve Certification status from the Center for START Services Certification Board to ensure that they have the expertise needed to provide NC START services and training with fidelity. Recruitment and retention of Coordinators has been a challenge. NC START East currently has nine certified START Coordinators. Plans include certifying three additional coordinators in the beginning of 2018.

2017 marks the ninth year of START services in North Carolina and much progress continues to be made in the Eastern region. This was the first year that NC START programs began serving children (ages 6-20) and of the 113 individuals served by the East this year, 42 (38%) were children. All NC START programs have now been using the SIRS database (START Information Reporting System) for three years. As seen throughout this report, the SIRS database enables our program to generate data-driven reports and measure clinical outcomes for the individuals served, both were previously unavailable to stakeholders. Service trend data reporting methods have also improved with the ability to report on the types of planned services offered throughout the year as well as from year to year. SIRS has also enabled us to track individuals' progress over time. The use of the Aberrant Behavior Checklist as a tool to measure changes over time is highlighted in this report. The reduction in overall scores for many of the individuals supported through START is a promising finding.

As the North Carolina system continues in a managed care environment, the structure and function of the system of support for individuals with IDD is also changing. Many individuals who were receiving START services in prior years also had an assigned care coordinator or case manager that worked collaboratively with START. Since the transition to a managed care coordination model that is designed to be short term, the START teams have found that individuals' team members are often changing, leaving individuals with significant needs with less service consistency than in the past. A growing number of children and especially transitional age youth requiring intensive assistance have emerged, with complex needs, and limited access to needed services. This has challenged the teams to be more creative in seeking system solutions.

NC Start East currently has a waitlist for both adults and children. The adult wait list began as a result of NC START East becoming a closed system in 2015 in order to do more outreach and secondary

intervention for those enrolled with START. The children's list started as a result of the referrals for children being open to anyone, unlike the Central and Western regions who receive referrals for children only from the MCO. This year the East was able to add additional coordinators and an additional clinical team leader which supported the enrollment of new members to START, accepting over forty new child cases before the end of the fiscal year. In an effort to be responsive to the state, the East worked to quickly enroll children and is still working toward eliminating the waitlist for adults. This is important in meeting the mission of START and will be a goal in the coming fiscal year.

In the short time that NC START has been a closed system, all three programs have been able to offer more community training and outreach across the state. NC East has partnered with the local AHEC, Cherry Hospital and Caswell Developmental Center to provide training to key stakeholders. NCSTART East has been holding CETs on a regularly occurring basis and has also provided training to the MCO care coordinators in their region. The East team has also been able to focus on the development of more linkages and collaborative relationships within their respective communities including a focus on children's service providers.

Other important achievements during 2017 include the securing of additional funding from the NC Department of Health and Human Services Division of Mental Health, Developmental Disabilities and Substance Abuse Services to provide children's services including therapeutic in-home mobile supports. This allowed for the hiring of a Clinical Team Leader, additional START coordinators and START Therapeutic Coaching Team lead and in-home coaches. This year, Trillium and Eastpointe also worked with RHA, NC START East and Dr. Beasley to develop a Professional Learning Community (PLC) made up of professionals across disciplines and agencies that meet on a regular basis to learn about evidence based, best practices in supporting children with IDD and co-occurring mental health conditions.

As in-home therapeutic coaching continues to be an integral resource for individuals, especially children and families enrolled in NC START, the program determined that one in-home team leader in conjunction with the Clinical Director and four START Therapeutic coaches were needed in order to provide the clinical and systemic support required to assure the successful provision of these services. At the closing of the fiscal year, these positions were filled and the team leader now directly supervises START Therapeutic Coaches.

START program certification is a rigorous process. Teams are required to demonstrate fidelity to the START model in all clinical and therapeutic supports/resource center service areas. The NC START East program was the second certified program in the county and received a two-year certification in March, 2015. In October, 2017, the East renewed their Program Certification for another two years. This certification is an accomplishment that should be celebrated by the program and as well as their partners. This achievement is especially vital given that programs previously doing so have demonstrated important successes in outcome measures such as a reduction in psychiatric emergency room evaluations and psychiatric inpatient stays.

Many important things have been accomplished in the eastern region of North Carolina this year with the commitment and dedication of the START program, the MCOs and other partners. We look forward to

discussion and next steps in the coming year. Thank you for your input as a valued partnership in this effort.

The report to follow provides a detailed analysis of NCSTART East for the 2017 fiscal year.

Contributors to this report and the information in it are:

Lisa Wolfe, MSW, LCSWA
Director, NC START East
lwolfe@rhanet.org

Priscila Norris, MS, MSW, LCSW
Clinical Director, NC START East
priscila.norris@rhanet.org

Laurie Charlot, LCSW, PhD
Developmental Psychologist

Recommendations from 2016 Annual Report/Progress

Following are the goals set at the time of completion of the FY 2016 annual report and a summary of progress.

1. Complete expansion of children's services including completing the process of hiring into new positions, training and deploying new hires and the development of the in home therapeutic services.
 - *The NC START East team was able to achieve this goal in the last year. With the hiring of a START Therapeutic Coaching Clinical Team Lead and four START Therapeutic Coaches.*
2. Continue collaboration with the MCOs to identify people at most risk in the system to provide comprehensive assessments and START coordination.
 - *The NC START Team was able to provide some targeted consultations to help individuals identified by MCO staff who were in critical need of our support.*
 - *Ongoing meetings with the MCOs to refer and discuss youth identified as meeting criteria for START Services.*
 - *Ongoing treatment team meetings with MCO representatives for all adults receiving Care Coordination, Transition Coordination, and individuals experiencing crisis events who do or do not have assigned Care Coordinators.*
 - *The NC START East team hopes to continue and enrich the START MCO collaboration.*
3. Work with representatives from the MCOs and other community partners to refine the process of initiating START services to individuals in need.
 - *NC START Team was able to collaborate with the MCO's on the waitlist for adults to identify those who qualify for the program, and to gather needed information regarding their needs. Due to this collaboration NC START East was able to narrow the waitlist for adults considerably and now has one of the shortest waitlists in NC. Continued collaboration is needed for START and the MCO's to eliminate the waitlist. NC START East is reviewing the waitlist on a regular basis and working diligently to start supporting individuals and plans to eliminate the waitlist by the end of the next reporting period.*
4. Train and prepare new coordinators for coordinator certification and expand current coordinators' expertise in work with children with IDD.
 - *The NC START East team made progress toward this goal in the last year. Two coordinators were certified during this time period. However, due to expansion and turn over, the certification process has been ongoing. All new START Coordinators will be scheduled to be certified by the end of FY*

2018. It is anticipated that there will be less turnover and recruiting, as noted, has already improved with more qualified candidates applying for coordinator positions.

5. Expand partnerships and linkages to include key stakeholders in the work with children with IDD.
 - *Several affiliations were updated and added this year including some signed by Intensive In-Home providers, and schools. Further work was done with multiple community partners to lay the ground work for expanding on additional linkage agreements.*
6. Continue close collaborations with the MCOs in implementing services for children.
 - *During this fiscal year, NC START East leadership met with representatives from Trillium and Eastpointe MCOs to discuss expansion into lifespan services and collaborated in planning the process for accepting new referrals.*
7. Continue to expand training and education and outreach system wide in an effort to reduce reliance on more restrictive and costly forms of care such as ED visits and inpatient psychiatric stays.
 - *NC START East team members provided a large number of trainings during FY 2017 to a wide array of community partners including Eastern Carolina University psychiatry residents, hospital Emergency Departments and other hospital departments, provider agencies, facilities (i.e. Caswell, Cherry Hospital), MCO Coordinators and other caregivers and service providers.*
8. Participate in a minimum of two Professional Learning Community programs aimed at increasing capacity in the system and strengthening partnerships in the work with children with IDD.
 - *NC START East hosted two Professional Learning Communities during the FY 2017, one in the Eastpointe area and one in the Trillium area. Trillium and Eastpointe worked with RHA, NC START East and Dr. Beasley to develop Professional Learning Communities (PLC) made up of professionals across disciplines and agencies that meet on a regular basis to learn about evidence based, best practices in supporting children with IDD and co-occurring mental health conditions.*
9. Clinical Director to continue work in state wide forums and panels addressing needs of children with IDD, including completing role in development of guidelines for rational use of psychopharmacologic treatment for people with IDD.
 - *NC START East had some changes in clinical oversight this year. Priscila Norris MS, MSW, LCSW is now the full time Clinical Director and is supported by both Dr. Jill Hinton, Clinical Director for the Center for START Services as well as Dr. Charlot (previous Clinical Director), a developmental psychologist. Representation continues with Dr. Hinton, however Mrs. Norris will soon be joining these forums as well. Mrs. Norris serves on the Board of Directors for the National Association of Social Workers for North Carolina and works to advocate for legislation supporting individuals with*

IDD. She also attends NASW local program unit meetings and collaborative in the community regularly.

10. Clinical Director (Dr. Charlot) to organize and oversee a training at the National Center for START Services second annual institute regarding the challenges to accurate diagnostic assessment of people with IDD and how this impacts prescription of psychoactive medications.

- *Dr. Charlot organized and moderated a special panel of experts addressing the topic. The sessions received very positive reviews and another similar panel is planned for next year's Institute.*

11. Seek new interns from East Carolina University from social work and psychology programs.

- *NC START East continues to be committed to increasing the knowledge base of new professionals and will continue to work with ECU to provide training experiences for students enrolled in BSW and MSW programs. Two interns worked with Start at the beginning of 2017 and two more are scheduled to work with the East team beginning in August 2017.*
- *NC START East has expanded in working with other colleges and universities as well including Simmons College and the University of New England.*

12. Continue to apply information from review of SIRS database to inform planning for the NC START East program. For example, a high rate of medical comorbidities was found so that increased training and consultations around this topic will be planned for the coming year.

- *An integral part of the START model is to improve the overall capacity of the system as a whole. In an effort to increase the capacity for providers to continue to offer community CETs and trainings around health issues.*

13. Increase nursing time to allow for use of the Center's RN to consult regarding health issues of children served.

- *NC START East was able to increase the nursing time with the program at the Resource Center as well as for clinical consultation. Most recently NC START East has begun working with a new nurse that has extensive history with working with individuals with IDD and behavioral health challenges. We have begun identifying training topics for the community.*

Findings

The following report provides an analysis of enrollment, demographic and service outcome data for the NC START East 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 East are based on data entered into the START Information Reporting System (SIRS) by program staff. The NC START East 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 East during FY17 (N=113). Individuals who declined services or were ineligible for START services and not included in this report. Past reports have considered children to be individuals under age 18, but in conjunction with the settlement agreement that expanded START services in NC to children, this report and all future reports will consider youth to be individuals under age 21.

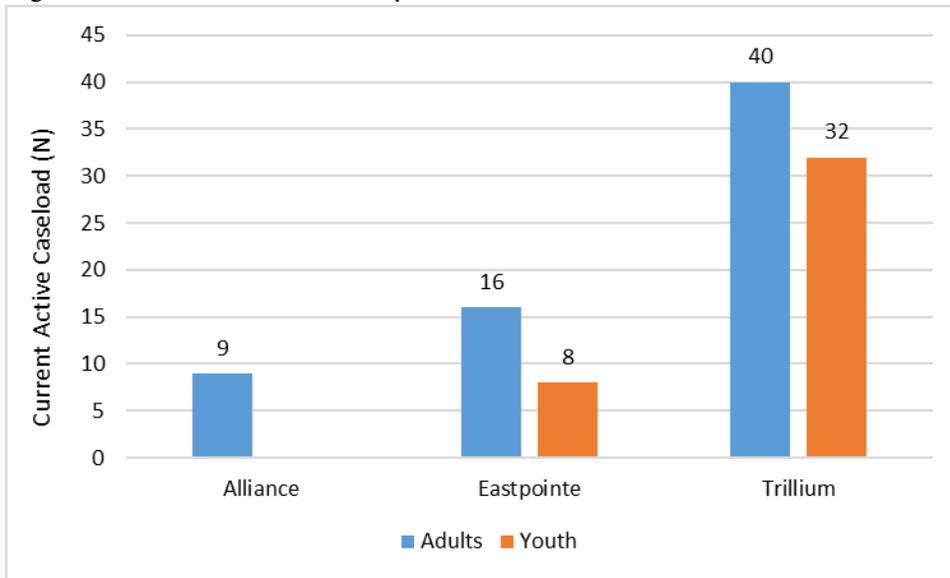
Table I.A: Enrollment Trends: Adults (21+ years old)

	FY17
Total Caseload at Beginning of Reporting Period	64
Individuals Enrolled During Reporting Period	7
Individuals Inactivated During Reporting Period	6
Total Caseload at End of Reporting Period	65
Individuals Served During Reporting Period	71
Percentage of Total Caseload	63%

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

	FY17
Total Caseload at Beginning of Reporting Period	2
Individuals Enrolled During Reporting Period	40
Individuals Inactivated During Reporting Period	2
Total Caseload at End of Reporting Period	40
Individuals Served During Reporting Period	42
Percentage of Total Caseload	37%

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 15 months for adults, which falls within the National average of 12 – 18 months.

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

Variable	Adults	Youth
N	6	2
<i>Reason for Inactivity (%)</i>		
Stable functioning	17%	0%
Moved out of START region	50%	100%
No longer requesting services	33%	0%

Table I.D: Source of Enrollment to START during this reporting period

Variable	Adults	Youth
N	7	40
<i>Source of Enrollment (%)</i>		
Service Coordinator	29%	85%
Community psychiatric inpatient	14%	0%
Residential/day provider	14%	0%
Mobile Crisis	0%	10%
Family Member	29%	0%
Hospital emergency department	0%	5%
State Operated IDD Center	14%	0%

Table I.E: Reasons for enrollment

Variable	Adults	Youth
<i>N</i>	7	40
<i>Most Common Reasons for Enrollment (%)</i>		
Aggression	100%	78%
Family needs assistance	14%	43%
Risk of losing placement	14%	25%
Mental health symptoms	43%	40%
Suicidality	0%	23%
Self-injurious behavior	29%	13%
Sexualized behavior	14%	18%
Leaving unexpectedly	29%	23%
Transition from hospital	14%	18%
Dx and planning assistance	14%	20%
Decreased ability to function	29%	23%

Summary

During FY 2017, a major focus for NC START East was the expansion of the program into child services. Though 7 new individuals aged 21 or older were enrolled, services to 40 children were initiated. The 7 adults were enrolled in the first half of the fiscal year and then the priority shifted to enrolling children. Processes for handling these referrals were being designed and trialed during the program development phase. This impacted the nature of services delivered to adults, as will be evident in subsequent sections of the report. For example, there were fewer crisis admissions to our Resource Center since this service is for adults. Overall caseload size will grow over the next FY and more adults will be enrolled. The pace of the growth of the program, as measured by the number of individuals served, was initially slow for FY 2017 because we were also hiring and training new staff. Presently, we have seven coordinator FTEs and two clinical team leads, but coordinator positions were not filled until the end of the fiscal year in 2017 and the second team lead was added at the beginning of FY 2018. NC START East will continue to seek qualified applicants for the positions and review strategies to retain trained staff. We will also evaluate the role of team leaders moving forward as well.

The low rate of adult referrals coming from Service Coordinators may be related to other characteristics of the adult population we serve, including their extremely low rate of waiver enrollment, which in turn means that care management services they receive are often short term. However, individuals with high levels of risk may still be identified by our MCO partners and these data suggest more work can be done to remedy this.

In keeping with historical data, the majority of individuals referred to START services were referred due to challenging behaviors, including verbal and physical aggression, self-injurious behaviors and property

destruction. In the current reporting period, this was the main reason for referral for 100% of the adults and 78% of youth enrolled in services.

It is important to note that this is the first reporting period during which data about youth were available for analysis. Though the large majority of children were referred related to “aggression,” there was also a high percentage of referrals listing “family needs assistance” as a primary or secondary reason for referral, including 43% of enrollees. This highlights the importance of crisis prevention and intervention services for youth residing in our region that can support children remaining with family members whenever possible. Also, this being the first year of serving children, the children referred have been in distress for some time.

When compared to adults served, youth were also more often referred for being at risk of losing their placement. Children with ID/D are more likely than adults, to enter the foster care system. Early intervention and familial support through education and crisis prevention will likely be critical to address this concerning trend.

Data should show a trend towards fewer referrals coming from inpatient units and more referrals from coordinators and agencies prior to the individual having to experience multiple ED visits and inpatient psychiatric stays.

Goals

- The NC START East team will continue to collaborate closely with stakeholders to enroll children, and will be working to reduce and eliminate the current adult waitlist by enrolling more adults. To that end, targeted outreach to MCOs will be initiated to encourage identification and referral of adults with risk issues.
- Data will be carefully monitored and all steps needed will be taken to insure caseload sizes rise during FY 2018, using data to inform case assignments across the various localities in our Region.
- Children with very complex needs who have already been removed from family homes, who need NC START East services, will continue to be enrolled. However, a goal will also be to collaborate with stakeholders to increase enrollment of children who are still at home with family, but who are demonstrating early signs of future risk of out of home placement.
- As with referrals for children, education to the system of care regarding the helpfulness of earlier referral for START services for adults with high rates of risk issues, will also be a goal.

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=113) 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

<i>Variable</i>	Adults (21+)		Youth (6-20)	
	FY17: NC East	FY17: Other START Programs	FY17: NC East	FY17: Other START Programs
<i>N</i>	71	1705	42	809
<i>Age (Mean)</i>	31	35	15	16
<i>Gender (% male)</i>	51%	60%	79%	76%
<i>Level of Intellectual Disability (%)</i>				
No ID/Borderline	3%	8%	12%	14%
Mild	54%	47%	43%	38%
Moderate	25%	26%	26%	26%
Severe-Profound	10%	9%	10%	7%
Level Unspecified	7%	6%	10%	13%
Missing	1%	3%	0%	3%
<i>Living Situation (%)</i>				
Family	44%	35%	57%	83%
AFL/Foster Care	10%	9%	12%	2%
Group Home and Community ICF/DD	30%	30%	14%	6%
Independent/Supported	6%	13%	0%	2%
Psych. Hospital/IDD Center	6%	3%	7%	2%
Other (Jail, Homeless, "Other")	1%	7%	5%	3%
Missing	4%	3%	5%	1%
<i>Funding Source (%)</i>				
IDD Waiver	18%	49%	10%	40%
Medicaid	72%	37%	86%	45%
Medicare	1%	1%	0%	0%
Private Insurance	1%	2%	0%	4%
State funds	1%	2%	2%	2%
Missing	6%	9%	2%	9%

Summary

NC START East serves an adult group with IDD that includes slightly more females and more individuals with mild cognitive impairment when compared to other START programs. A more significant difference between adults served in eastern NC and those served elsewhere relates to waiver access. As indicated above, adult START enrollees in eastern NC are three times less likely to be served under a waiver. Children enrollees are also far less likely to be receiving waiver services. For both groups, this means restricted access to some key services, especially those that might support less restrictive settings and aid in keeping children in family homes. This is critical when added supports are needed secondary to co-occurring conditions (having both ID/D and a mental health disorder). In fact, children enrollees are less likely to be living at home and much more often, are being placed in facility based or group care settings.

Both children and adult enrollees in eastern NC are far less likely to be served on a waiver than are individuals served in other START programs. The living situation and funding source for adults is consistent with previous years. Medicaid continues to be the primary funding source, which is almost double the frequency of this funding stream when compared to other START programs across the US.

One of the main difficulties with supporting individuals who are only eligible for receiving Medicaid funded services is that they are not eligible for ongoing Care Coordination and case management. Care Coordination is designed to be short-term and focused on referrals and linkage, which means that individuals with more complex needs, such as the ones supported by the START program, may receive less consistent support and less intensive evaluation of service effectiveness. This, in turn, may contribute to a longer involvement in START services and a need for case re-activation due to loss of stability, interruptions in continuation of care, and destabilizing changes in service provisions and team member changes.

Goals

- Work with stakeholders and at advisory board meetings to raise awareness of concerns listed above, illustrated in the data provided.
- Develop strategies to address needs for supporting access and appropriateness of care need to help children remain with family and adults to reside in less restrictive settings.
- Increase primary intervention strategies such as outreach and training to existing family support groups.

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 influences 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

Variable	Adults (21+)		Youth (6-20)	
	FY17: NC East	FY17: Other START Programs	FY17: NC East	FY17: Other START Programs
<i>N</i>	71	1705	42	809
<i>Mental Health Conditions (%)</i>				
At least 1 diagnosis	97%	84%	100%	78%
Mean Diagnoses	1.9	2.0	2.6	2.1

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

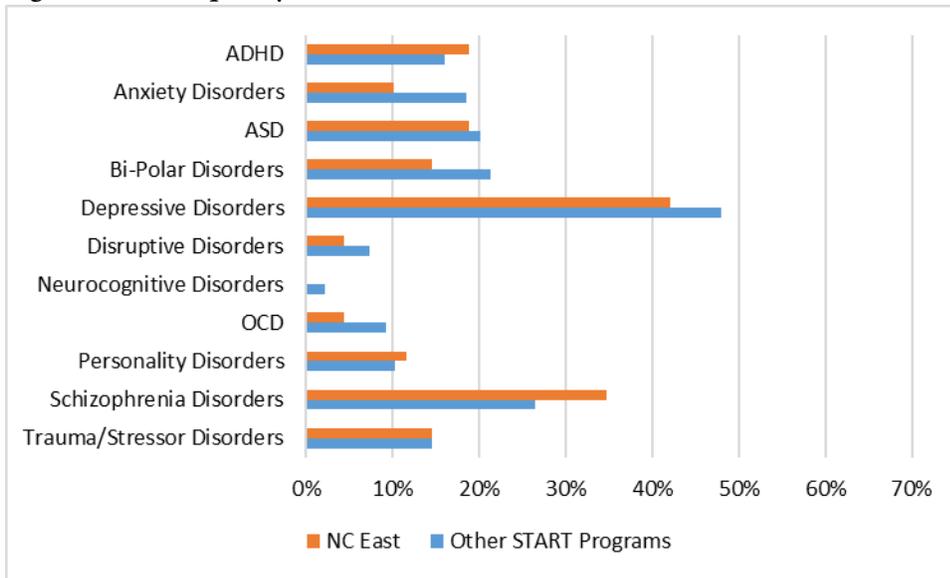
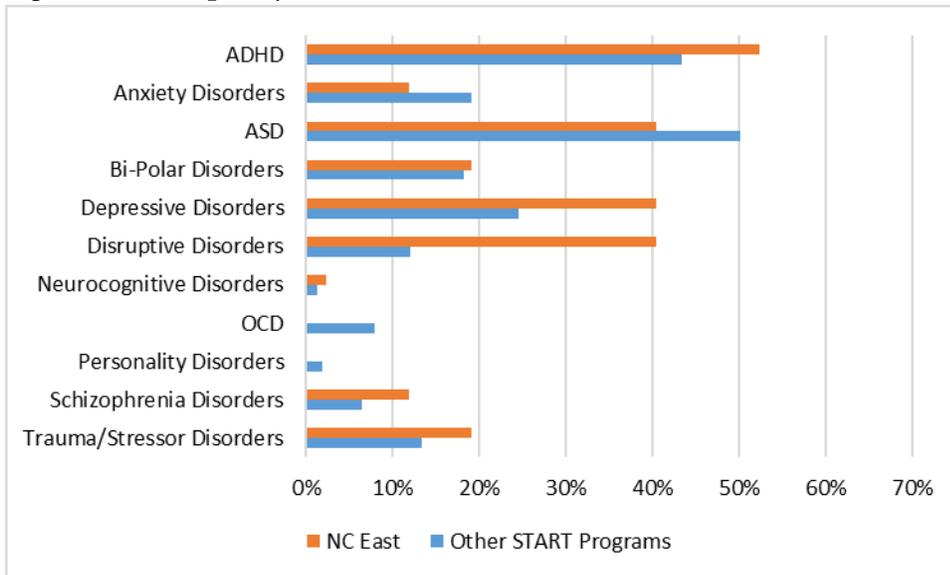


Figure II.B: Frequency of most common mental health conditions for enrolled youth



Summary

Only about 3% of adults served in this reporting period did *not* have a mental health diagnosis listed at the time of enrollment. A full 100% of youth served had at least one mental health diagnosis, with an average of 2.5 diagnoses reported for each youth. This is higher than the national average, and may be related to the nature of referrals from the region including many youth served in congregate care settings. Presence of multiple diagnoses often reflects less reliability of diagnoses and diagnostic confusion. Access to child psychiatry may be restricted in some parts of the region and could contribute to this trend.

Autism Spectrum Disorder (ASD) diagnoses in NC East child enrollees was about 10% lower than the national average. This is likely related to limited access to providers able to conduct ASD screenings and assessment in rural eastern North Carolina. Adult rates are lower for most START enrollees. ASD may *not* be a less frequent comorbidity in populations of adults with ID/D and behavioral health issues. Rather, ASD be missed in adults who had developmental evaluations years ago, prior to the development of more reliable and valid assessment practices, and before expansion of diagnostic criteria. In some cases, adults with ASD who have difficulty coping with changes and unstructured life circumstances become mislabeled with psychiatric conditions such as schizophrenia.

In a subset of adults who were assessed by the NC START East Clinical Director and/or Medical Director during emergency stays at our Resource Center (n = 10), possible alternative diagnoses were identified for 5 individuals. Most of the adults for whom an alternate diagnosis was provided, had previously been diagnosed with a psychotic disorder. A similar careful review of a sample of child cases demonstrated that most children were diagnosed with oppositional defiant disorder when their symptoms pointed to ADHD and/or anxiety. In general, it has been concerning that a majority of individuals served by our program had some experience of extreme stress or trauma in their past, but few were diagnosed with Post Traumatic Stress Disorder, and many received treatment with antipsychotic drugs without receiving trauma informed care.

The most frequent diagnosis among child enrollees was ADHD. Though ADHD is a highly frequent comorbidity of ASD, rates in clinical populations of youth with IDD are less clear. In general population research using strict criteria and reliable assessment methods, rates are higher for children with borderline or mild ID, when compared with typically developing youth. However, many occurrences of mood and behavioral challenges are the result of the combined effects of cognitive impairment and/or ASD plus exposure to stressful contexts and can be mistaken for evidence of conditions like ADHD. Further, factors such as anxiety and poor health (missed medical problems) may disrupt attentional processes and provoke restlessness that may give the appearance of an ADHD. Research has demonstrated that children diagnosed with ADHD and ID/D respond less well to stimulants, when compared with youth with ADHD only. This is likely related to over-diagnosing ADHD in youth with an ID/D.

Our data also shows that 40% of enrollees had a depressive disorder diagnosis, as compared with approximately 15% who were diagnosed with bipolar disorder. These data are reassuring given that well controlled studies have demonstrated this to be a usual ratio for the two types of mood disorders. Individuals with ID who have a Major Depressive Disorder often present with irritable mood, aggression and motor restlessness that can be misinterpreted as mania. DSM 5 describes a new diagnostic category, Disruptive Mood Dysregulation Disorder (DMDD). The newly suggested syndrome was identified to capture youth who formerly may have been diagnosed with Bipolar Disorder, but did not meet criteria due to a lack of an episodic pattern of illness and absence of expansive mood states. It was hoped this would help address a national trend to over diagnose youth with bipolar disorder (and related to this, to rely on very complex medication regimens). However, it is unclear how DMDD will be applied as a syndrome in the assessment of children with ID/D, or what types of treatment will be most helpful.

The low occurrence of anxiety diagnoses in both the adult and youth populations is a point for further exploration. Anxiety disorders are the most common comorbidity found among youth with an ASD, and occur quite frequently in adults (with and without ID/D). It has been speculated that anxiety is likely missed when the focus of clinical attention is on externalizing symptoms (aggressive and disruptive behaviors). These symptoms are often, in fact, a surface manifestation of anxiety (fight or flight) in populations less able to reliably report about internal states.

Rates of schizophrenia diagnoses in the adult population continue to be higher than the national average. Psychotic disorders may be over diagnosed in individuals with ID/D though trends vary regionally. This can be the result of a lack of appreciation of the impact of an individual's developmental profile on the expression of distress.

Goals

- Clinical Education Team (CET) trainings will be conducted at least monthly, coupled with outreach to stakeholders to increase attendance. These CETs provide a forum for educating participants in understanding unique issues related to accurate differential diagnosis of psychiatric conditions in people with ID/D and include case based training provided by the Medical and Clinical Directors of the NC START East team. An overall aim is to enhance the skills and expertise of community clinicians in diagnosis and treatment.
- Provide individual consultations from the Medical and Clinical directors to teams serving enrollees for whom there is ongoing diagnostic confusion.
- We will also increase utilization of our Resource Center as a means for data collection over time and assessment of the mental health status of adults.
- The high percentage of children diagnosed with ADHD has been a consistent trend in the region. Training for the team and to the system on differential diagnosis related to ASD, ADHD, anxiety disorders, and trauma related disorders may be helpful in addressing community providers' needs to enhance their skills in differential diagnosis,

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

Variable	Adults (21+)		Youth (6-20)	
	FY17: NC East	FY17: Other START Programs	FY17: NC East	FY17: Other START Programs
N	71	1705	42	809
<i>Chronic Medical Conditions (%)</i>				
At least 1 diagnosis	85%	66%	45%	51%
Mean Diagnoses	2.4	2.1	1.8	1.6

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

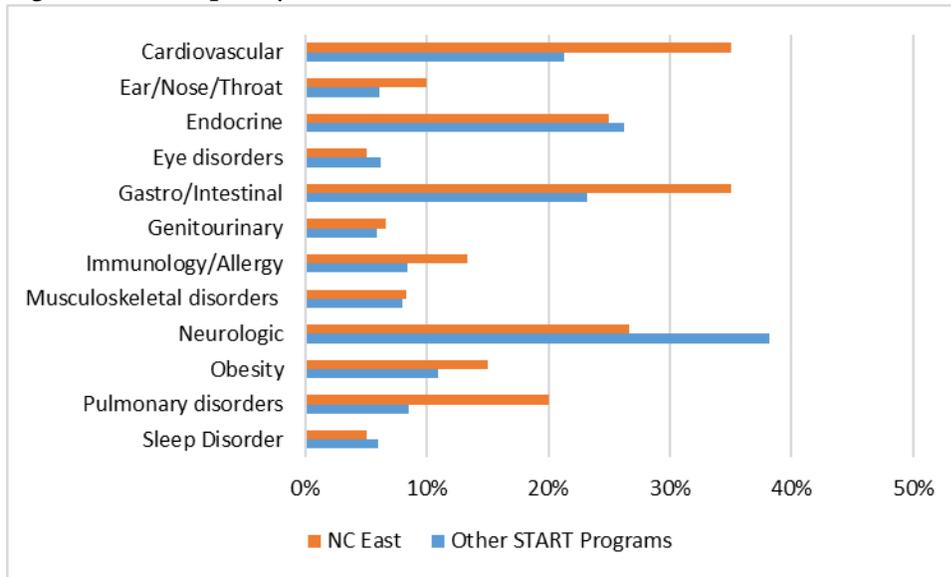
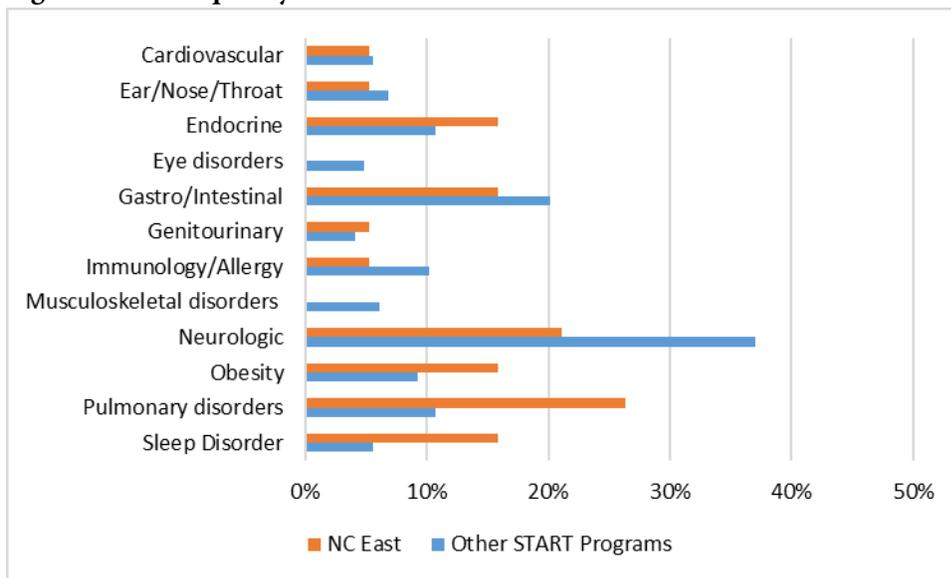


Figure II.D: Frequency of most common chronic medical conditions for enrolled youth



Summary:

Medical conditions are frequently difficult to assess in individuals with ID/D due to a variety of issues such as communication challenges, anxiety regarding examination and access to care. As a result, even some common health concerns may be missed. Further, medical conditions are associated with alterations in mood and behavior that can lead to the misattribution of emotional and behavioral symptoms to a psychiatric condition.

70% of all individuals enrolled in NC START East during this reporting period have chronic medical conditions, as compared to 61% reported nationally. This may be related to efforts over the past year to insure that data regarding all health conditions were being recorded, as even known conditions may be omitted from certain records. Also, a goal set last year for NC START East was to increase education regarding medical conditions and medication side effects that may be missed and has raised awareness of the significance of capturing this information at intake.

The prevalence of medical conditions for individuals with ID/D is higher than that found in the general population. Several factors likely contribute to this trend including the association of health problems with syndromes that are known to cause ID/Ds. Also, individuals with ID/D as noted above are poor reporters of their own health histories and symptoms, while there is a need to rely on informant reports. Higher rates of medical problems may be related to over reliance on psychoactive medications in the population and undetected or under-appreciated side effects such as headaches, sedation, orthostatic changes, muscle stiffness and restlessness. Gastrointestinal issues such as constipation and acid reflux are highly common, as are problems related to dental concerns.

Goals

- Our goal is to continue efforts to promote health and wellness for individuals we serve. START coordinators are trained to encourage, promote and provide resources that promote healthy lifestyles, and this philosophy is put into practice at START Resource Centers as well as coordinators' work during outreach visits.
- An additional goal is to strengthen our collaboration with ED staff to promote more comprehensive medical screening during crisis assessments that occur in this setting. Over the past year, NC START East had multiple Resource Center admissions during which guests required urgent care or ED visits due to medical concerns when the guest had just been in the hospital or another ED.
- The NC START East Medical Director and Clinical Director will be conducting assessments during Resource center stays and will provide other consultations to advocate for multi-modal care to help reduce over-reliance on medications as the main intervention for behavioral health problems by sharing impressions and recommendations with caregivers and treating clinicians.
- Based on a review of these data, more training regarding physical health, medication side effects and the connection these regularly have with behavioral health challenges is warranted. Dr

Charlot, consultant to NC East team and a former director, continues to work with a statewide group initiative to develop a set of guidelines for psychoactive medication treatment in both youth and adults with IDD that will include references to identifying common medical problems and medication side effects that can provoke a clinical picture that may mimic mental illness. She will be providing community based trainings that address these topics throughout the upcoming fiscal year.

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 as well as decrease in emergency department utilization for enrolled youth.

Table III.A: Emergency Service utilization

	Adults (21+)	Youth (6-20)
<i>N</i>	71	42
<i>Psychiatric Hospitalizations</i>		
Prior to enrollment, N (%)	52%	60%
Mean (range)	1.9 (1-4)	1.6 (1-3)
Percent with Multiple Admissions	61%	48%
During START, N (%)	38%	7%
Mean (range)	2.6 (1-11)	1.0 (1)
Percent with Multiple Admissions	32%	0%
<i>Emergency Department Visits</i>		
Prior to enrollment, N (%)	79%	69%
Mean (range)	3.3 (1-17)	3.5* (1-39)
Percent with Multiple Visits	57%	68%
During START, N (%)	46%	21%
Mean (range)	4 (1-21)	1.6 (1-4)
Percent with Multiple Visits	64%	33%

*Excludes outlier (range 1-14)

Summary

Adults and children served in the East have very high rates of emergency department utilization prior to enrollment in START. In addition, there is a very high percentage of individuals utilizing the ED multiple times within a year.

In the year prior to enrollment in START services, about 55% of all service users in the East had a history of psychiatric hospitalization. Following enrollment, less than 22% were hospitalized for psychiatric reasons.

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.

Low rates of Emergency Department utilization is often seen as a measure of stability for the individual and system. Prior to enrollment, 74% of individuals in the East had a history of one or more emergency department visits. Following enrollment, only 33.5% 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 is experiencing an acute crisis.

Goals:

- The use of emergency departments prior to START is especially high for the individuals who are enrolled. While there is a substantial reduction in this with START involvement, the over-reliance on the ED continues to be a trend in the system. It would be helpful to identify if the ED use is more frequent among individuals who live with families or those who live in residential settings. This could lead to development of targeted strategies including outreach, training, and refinement of the cross system crisis plans.

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 Region 1 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 START 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	87	83
Community-based training	11	12
Host Advisory Council Meeting	5	4
Provided training to day provider	4	4
Provided training to emergency services	4	5
Provided training to family	1	6
Provided training to other	0	14
Provided training to physician/medical personnel	3	8
Provided training to residential provider	6	6
Provided training to school	1	6
Provided training to state facilities (state hospitals, developmental centers)	6	4
Provided training to therapist/mental health providers	2	4
Time spent on affiliation and linkage agreements	13	18
Transition Support/Planning-Developmental Center	4	3
Total Outreach Episodes	154	171
Linkage/Collaboration Agreements	28	34
Clinical Education Team (CET)	5	8

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.

- Double Jeopardy Trauma and Intellectual and Developmental Disabilities
- Why Risperidone Won't help your Toothache
- Autism: Growing up Uniquely

- Detecting Medication Side Effects in Individuals with I/DD
- Thinking outside the Box: Helping Children with I/DD and ADHD
- Crisis Intervention Training for law enforcement throughout the Eastern region in conjunction with MCOs.
- Trainings for various providers including mental health and I/DD residential providers, ACTT team ICF, PSR, IDD day programs, MCM, etc.
- Training for Trillium and Eastpointe MCOs
- NC NASW recorded Webinar: Assessment and Diagnosis of dually diagnosed individuals
- East Carolina University School of Social Work
- Mental Health aspects of I/DD
- Overview of NC START East
- Crisis prevention and Intervention for people with I/DD
- 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.⁷
- 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

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 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 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

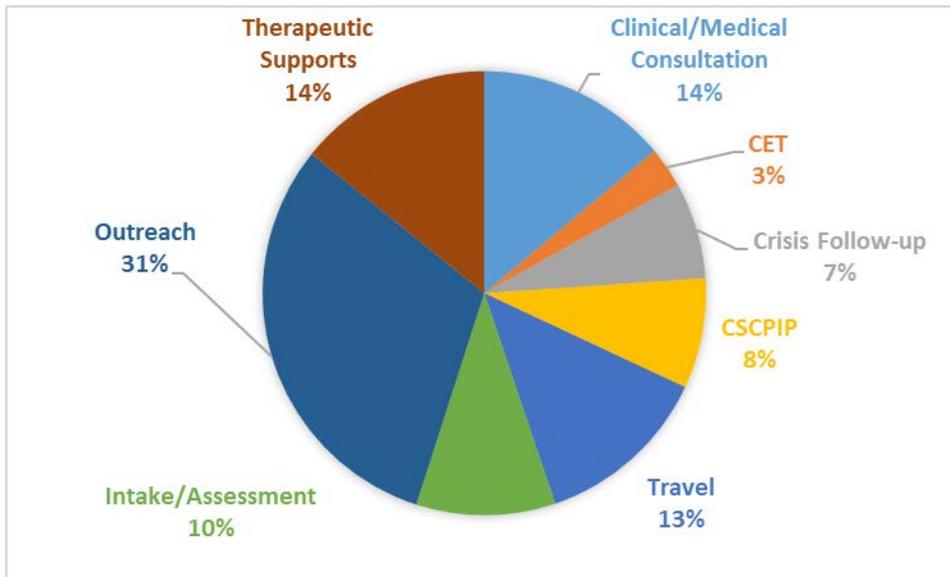


Figure IV.B: Planned Service Utilization Trends (Percent of Adults)

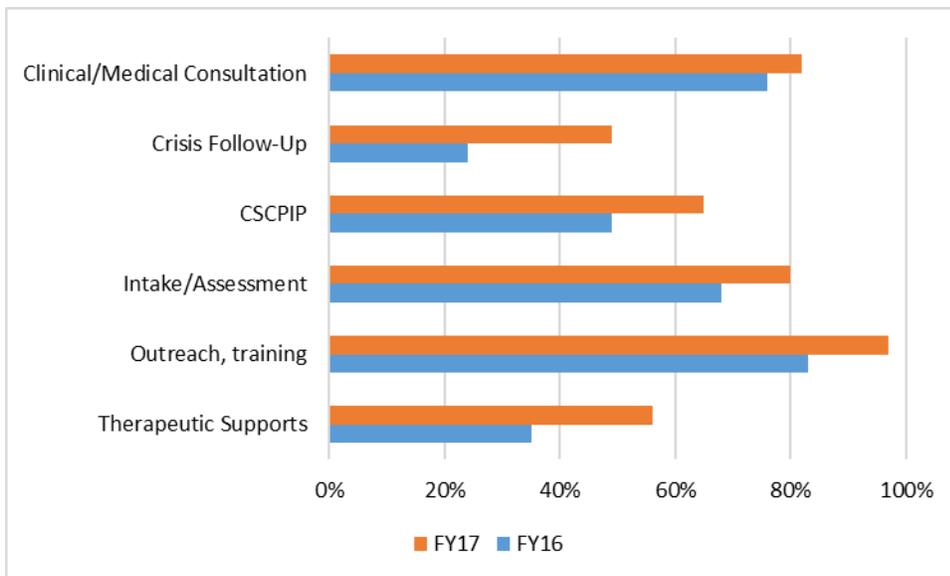
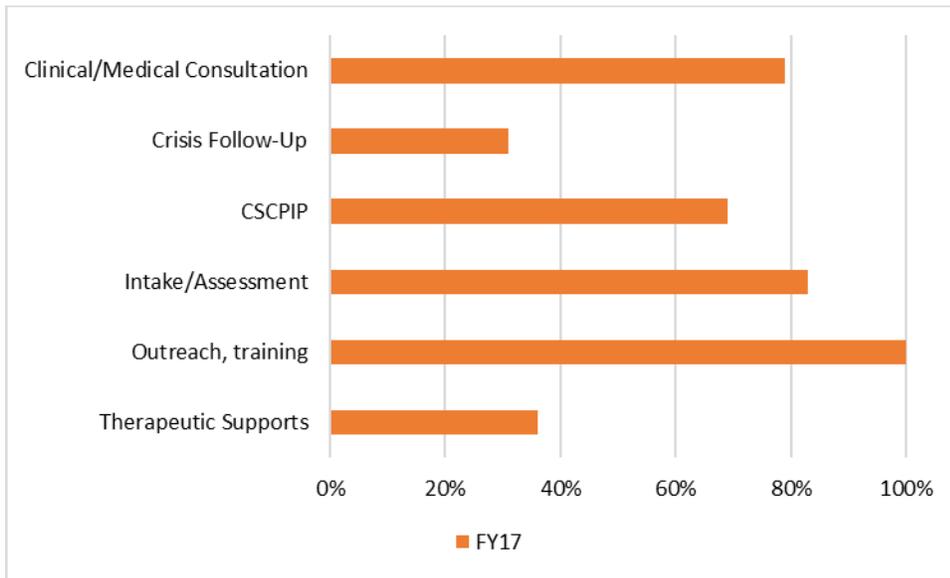


Figure IV.C: Planned Service Utilization (Percent of Youth)



Summary

As the data shows, the NC START East team has significantly increased utilization of planned services in the region for adults, and has begun to provide these services for youth during the reporting period. The increase was due to an increase in the size of the team, which in turn allowed for a re-focus of efforts and resources on crisis prevention through better utilization of planned services. At the end of the last reporting period, the team was comprised of the director, clinical director, medical director, seven coordinators, one Clinical Team Lead, Resource Center Director and Resource counselors. At the beginning of this reporting period, the team added the first clinical first team lead. In the second quarter of the reporting period, the team added three more coordinators. With a team of seven coordinators and a team lead, the program was able to refocus efforts and resources on providing more intensive outreach and training, which totaled 31% of the time spent during the reporting period, as shown in figure IV.A. This also resulted in an approximate 20% increase in the number of individuals whose systems received outreach and training. In addition, the program was also able to increase the amount of time spent on intake and assessment activities from 4 % to 10 %. The Intake and Assessment allow for data-driven, clinical and systemic needs assessments. These in turn yield a more thorough case conceptualization, engagement, and treatment.

It is important to note that individuals who are active START clients throughout the year may not receive every planned service listed above. For example, not all individual requires a medical consultation or the development of a new Cross Systems Crisis Prevention and Intervention Plan. Plan updates take considerably less time than the development of a new plan for newly enrolled individuals. In addition, the data shows that most individuals served during the reporting period received more than one planned service.

This time analysis also shows that efforts in crisis follow up have doubled since the last reporting period. This service includes emergency service admissions and discharges, meetings with emergency service providers and follow-up on crisis plan recommendations and is vital to reducing and preventing future crisis events.

Goals

- Provide additional training to Coordinators to help differentiate between “outreach” and “time spent on Intake/Assessment activities” categories in SIRS to more accurately capture the data.
- Increase time spent on CETs
- Increase compliance with CSCPIP development for all cases

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.

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
<i>START Action Plan</i>	98%	96%
<i>Aberrant Behavior Checklist (ABC)</i>	98%	96%
<i>Recent Stressors Questionnaire (RSQ)</i>	93%	95%
<i>Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)</i>	96%	90%

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=69). There are not currently enough children meeting the criteria to break this analysis out by age.

For those individuals receiving services with at least two administrations in SIRS (n=69), results show that average scores decreased in each subscale as shown in Table IV.

Table IV.C: ABC Analysis

NC East (N=69)	Percent with Improvement	Mean Score		t Stat	P(T<=t) one-tail
		Initial	Most Recent		
Hyperactivity/Noncompliance	64%	18.14	13.94	2.98	0.00
Inappropriate Speech	54%	4.03	2.84	3.16	0.00
Irritability/Agitation	71%	20.28	15.51	3.65	0.00
Lethargy/Social Withdrawal	59%	10.91	9.30	1.69	0.05
Stereotypic Behavior	54%	3.90	2.41	2.51	0.01

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.

Goals

- The National START Team will work with NC START 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

NC START 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.D: FY17 Crisis Contacts

	FY16	FY17	
Crisis Contacts	FY16	Adults (21+)	Youth (6-20)
Total individuals	34	39	16
Total number of crisis contacts	164	156	56
Average number of contacts	4.8	4.0	3.5
Number of individuals with more than 1 Emergency/Crisis services	19	28	10
Percent of individuals with more than 1 Emergency/Crisis services	56%	74%	63%

Table IV.E: Type of Crisis Response

	FY16		FY17	
Type of Response	N	%	N	%
In-Person	25	15%	57	27%
Phone consultation only	138	84%	150	72%
Unreported	1	1%	5	2%
Total Contacts	164	100%	212	100%

Table IV.F: Outcome of Crisis Contact

Outcome of crisis contact	FY16		FY17	
	N	%	N	%
Maintain current setting	98	60%	144	68%
Psychiatric hospital admission	15	9%	10	5%
Emergency Department	3	2%	0	0%
Emergency Department hold	10	6%	35	17%
Referral for services	7	4%	3	1%
Crisis Stabilization	8	5%	1	0%
Medical Evaluation/Admission	0	0%	1	0%
START Emergency RC admission	14	9%	13	6%
START Planned RC stay scheduled	3	2	1	0%
Other	2	1%	4	2%
Unreported	4	2%	0	0%
Total Crisis Contacts	164	100%	212	100%

Table IV.G: Reason for Emergency Department Hold

Reason for ED Hold	FY16 (N)	FY17 (N)
Medical Stabilization	0	1
No hospital beds available	1	17
No placement available	5	12
Assessment	0	3
No funding for placement available	3	0
Other	1	2
Total	10	35

Summary

The frequency of In-person crisis response increased from FY 2016 to FY 2017, which is a desired trend.

Despite large increase in number of calls, we improved response time in person from over five hours to less than three hours. This is most likely accredited to the growth of the program as a whole.

The reason for the high number of individuals held in the ED also includes children, in contrast to the previous FY. Finding inpatient treatment facilities who are able to accept children continues to be a challenge in our region. In addition, children are often held in the ED while alternative community placement is being sought. This information is also now being better tracked through SIRS

Goals

- Continue new system in place for tracking calls to assist team in documenting/reporting crisis calls to ensure accurate reporting of calls received.
- Continue to increase rate of in-person responses.
- The leadership team will continuously review individual cases with high number of crisis calls and will develop a plan for more intensive outreach
- Collaborate with stakeholders to develop more appropriate protocols for addressing the large number of children being held in the emergency departments
- Continue to advocate for children, especially for those with high number of use of emergency services, to access targeted case management to help address care and placement needs that may lead and/or contribute to loss of placement and holding at the emergency department
- Collaborate with emergency departments with high utilization to complete emergency assessments with focus on appropriateness of placement and treatment needs, and conduct outreach to these emergency departments quarterly to offer training and education to ED staff

Section V: START Therapeutic Resource Center Services

Table V.A: Planned Resource Center Stays

Planned Resource Center Stays	FY16	FY17
Number of individuals	30	29
Total number of stays	104	117
Range of days	1 to 14	3 to 14
Average Length of Stay (Days)	6	6
Total time spent in resource center (in days)	625	740
Number of individuals with more than 1 Resource Center - Planned	19	22
Percent of individuals with more than 1 Resource Center - Planned	63%	76%
Occupancy Rate (2 beds X 365 days): 730 days	86%	101%

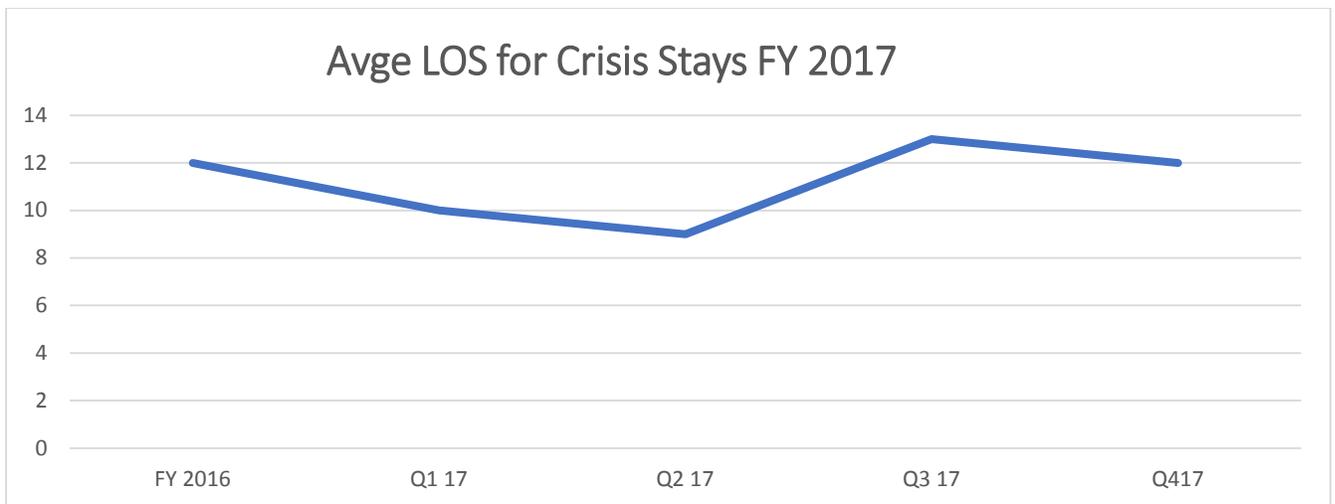
Table V.B: Emergency Resource Center Stays

Emergency Resource Center Stays	FY16	FY17
Number of individuals	20	15
Total number of stays	41	35
Range of days	4 to 31	1 to 29
Average Length of Stay (Days)	12	12
Total time spent in resource center (in days)	483	403
Number of individuals with more than 1 Resource Center - Emergency	9	9
Percent of individuals with more than 1 Resource Center - Emergency	45%	60%
Occupancy Rate (2 beds X 365 days): 730 days	66%	55%

Summary

NC START East added 13 additional planned stays from last year with an increase of a 100 days being used for planned stays. There was also an increase in the percentage of individuals returning to the Resource Center with the purpose of crisis prevention. This may be taken together with data reviewed above showing decreased measures of psychopathology and reduced ED visits and psychiatric hospitalizations to support efficacy of application of the START model in improving outcomes for enrollees, many of whom have histories of high rates of restrictive and expensive service use.

Of the 9 individuals who had a return crisis stay at the resource center, 6 returned only one other time during the fiscal year. Most (6 of the 9) returning individuals were supported through mental health services that often times that left gaps in their services and supports. The East has continued to have returning emergency resource center guests and this is something that should be explored further in the upcoming year. Return crisis visits to the resource center can occur for many reasons and may allow the START team to increase their understanding of the individual and in turn better support the family and/or provider. This trend might also be a sign of inconsistent supports and services and a need to wrap services around these individuals more consistently.



The rate of emergency stays was low this year again. In FY2017, this likely stemmed in part from a lack of new adult enrollees. After participation in START services over time, the adults who have formerly used the Center for crisis stays should be coming for planned stays to prevent crises. Planned stays were scheduled as often as possible, as noted, for prevention of crises and skill development/promotion of wellness. However, it remains very concerning that there has been a low rate of in person evaluations *and* a low crisis bed utilization, and increasing crisis bed utilization must be a high priority in FY 2018.

Goals:

- It is very important that crisis bed utilization increase consistent with regional needs and with other START programs.

- A first step will be to do an in-depth review of crisis calls, again to examine if more in person assessment could lead to better use of open crisis beds.
- Additional review will be conducted to identify all NC START enrollees with high levels of need ratings on START plans to examine if opportunities were missed to make use of these beds. Practice changes then will be made based on findings to increase use of crisis beds, such as identifying individuals at risk earlier in the chain of escalation for use of these beds.
- A detailed plan of action will be developed to address barriers to utilization identified in these reviews.

Conclusions and Goals for FY18

Conclusion

NC START East has experienced a great deal of change and growth during this past fiscal year. The team tripled in size, with expansion into children's services. Moving forward, the team will continue to focus on formalizing linkage agreements and ensuring outreach. Because of the expansion into child services, there is need for more aggressive outreach to providers of children's services both for the development of linkages, and to offer and provide consultation and training. In the process of developing children's services, we have had the opportunity to closely collaborate with our MCO partners and to share and learn from each other. Another major achievement this FY has been the development of our in-home coaching program. A START Therapeutic Team Lead was hired and the START Therapeutic Coaches were hired during FY 17 with the first referrals beginning in January 2017 and the first case opened for STC on February 15, 2017.

Our two PLCs were also extremely successful and helped build relationships in the system of care for people with ID/D. We have been able to provide routine case based trainings and are now able to offer CEUs, and we continued to work towards increasing our overall primary level services. Over the course of the year, we were able to increase the rate of outreach services and preventive secondary level interventions, and have been able to provide a large number of planned Resource Center stays. Our collaborations with Police Departments and provision of CIT trainings expanded this year as well. It was positive to see that the rates of ED use and psychiatric inpatient stays are lower for individuals served following enrollment in START. This was especially positive given that NC START East has a number of new team members. Intensive training of new START team members and receiving significant support from the National center for START Services has also been very helpful this FY. An ongoing goal is to continually reduce the use of these more expensive and restrictive forms of care. NC START East team members were able to provide a large number of trainings and a number of individual consultations, including training provided to psychiatry residents and fellows at ECU, many of whom will likely be prescribing and caring for individuals with dual diagnoses in our region in the future.

A few key concerns will require special attention in FY 2018. There is ongoing evidence that compared to people served in most other START programs, individuals receiving services in eastern NC are much less likely to be on a waiver. As a result, access to service options that can be helpful to many people with dual

diagnoses of ID/D and mental illness are unavailable to these individuals. This does not change our commitment to providing consultation and training to the system of care. Although access is important, we recognize there is always room to work on improving the appropriateness and quality of the services that are available.

Our data demonstrated that children with ID/D and significant behavioral health needs who we serve in eastern NC are too often being placed away from family and in more aggregate care settings. This again may be related in part to their access to services, and to access to appropriate evidence informed services. There is also ongoing challenges related to START enrollees having long stays and problems with regard to returning to their homes once they have experienced a crisis and have been seen in an ED.

A critical ongoing concern is under-utilization of our Resource Center crisis beds. The NC East team is already in the processes of increasing caseload sizes to ensure cost effective services, eliminate wait listing and also to reduce the problem of individuals lingering in Emergency Departments. The need to increase the percentage of in person responses to crisis events is also an important area for work in the coming year.

Maintaining fidelity to the START model is essential throughout these changes. The Focus will continue to be on program integrity as well.

Goals for Fiscal Year 2018

1. Increase caseloads to approximately 25 cases per coordinator. As part of this effort, eliminate the adult wait list and increase crisis bed utilization at our Resource Center.
2. Collect and review detailed data regarding the nature of our crisis contacts and review these to inform practice changes in regards to conducting more in person evaluations, which in turn may result in improved prevention efforts and greater utilization of crisis beds.
3. Continue to apply information from review of SIRS database to inform planning for the NC START East program.
4. Expanding partnerships and linkages to include key stakeholders in the work with children with IDD.
5. Develop a training series for children's mental health residential services in the NC START East region and expand training for children's services.
6. Seek new interns from East Carolina University as well as other universities and colleges from social work and psychology programs.
7. Continue to initiate services to individuals who are waitlisted, working with stakeholders to identify those most in need.
8. Continue to work on education and training of caregivers and agencies to reduce the numbers of people referred who are in serious states of crisis when referred, and increase earlier identification and referral of individuals at risk.

9. Increase clinical capacity by hiring an Associate Clinical Director.
10. Train and prepare new coordinators for certification and expand current coordinators expertise in work with children with IDD.
11. Continue to enhance the programmatic activities at the Resource Center by increasing clinical staff presence and developing additional therapeutic activities and providing more training.
12. Achieve and maintain full capacity of the Therapeutic Coaching Program.
13. Team will work with the National START Team to develop a protocol for using the FEIS instrument. FEIS data will be used to evaluate the work of START in improving family members' reported experiences of the mental health care their family members receive.
14. Leadership team to organize and oversee a training at the National Center for START Services third annual institute.