NC START

Systemic • Therapeutic • Assessment • Resources • Treatment

North Carolina START Program: West 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

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.

During FY 2016, additional funding from the NC Department of Health and Human Services Division of Mental Health, Developmental Disabilities and Substance Abuse Services was allocated to provide children's services including therapeutic in-home mobile supports, additional coordinators and other key positions (i.e. Team Leads) to allow an expansion into child services consistent with the national START model.

Over the course of FY 2016, the NC West START program, the MCOs and other partners have all worked to improve the lives of individuals with ID/D and significant behavioral health needs in our region, and have begun to expand services to children with complex needs.

NC START West has worked diligently this past year to implement lifespan services with the assistance of the National Center for START Services and the State of North Carolina, and in collaboration with our LME/MCO partners. In August, 2016, acceptance of referrals for children/adolescents from the MCO's in the NC West region began. During this past year, 62 children have been enrolled and received START services.

The program development phase of START Therapeutic Coaching service has been completed. NC START West recently filled all coaching positions, and training is underway in preparation for in-home coaching with families and children in our region. START Coordinators have made referrals and therapeutic coaching services will begin soon in FY18.

NC START WEST received National Certification in April 2017. Certification is a rigorous process that requires fidelity to the START model at all levels of service provision. START is an evidence informed model of care with national recognition. Initial research regarding the efficacy of the model has shown extremely promising results, with reductions noted in emergency service use and improvements in functioning reported for a large percentage of recipients of the service.

Our Resource Center moved into its new location in March 2017. The new Center provides ample space and opportunity for our guests to enjoy a variety of therapeutic activities as well as private areas for relaxation and individual meetings with Resource Center counselors and clinical staff. In recent months, we have focused on increasing the variety of therapeutic activities and enhancing clinical presence. Planned Resource Center stays are arranged for enrollees to provide opportunities to learn new skills to improve

individuals' abilities to manage anxiety and stress, and to collaborate with caregivers to improve their ability to support individuals with complex needs. These stays help to prevent the need for emergency services for many individuals. Crisis stays are needed at times, and the NC West team conducts a very comprehensive assessment and conducts close collaboration and outreach with individuals' teams when such a stay has been arranged.

In collaboration with the National Center for Center for START Services, NC START West has worked to implement all aspects of the START model with fidelity. An essential aspect of the model is data collection. Through the START Information Reporting System (SIRS), all elements of service delivery along with de-identified information about service users are entered into a database in order to evaluate our outcomes and compare those to national trends. The report to follow provides a detailed analysis of NC START West services for FY2017.

Contributors to this report and the information in it are:

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Goals from 2016 Annual Report/Progress

1. Obtain full certification:
   In April, 2017, our program obtained National Certification.

2. Hire and cross-train for all positions needed for adult and children's program:
   All positions for adult and children's program were filled. Coordinators were cross-trained for adults and children, as most carry a mixed caseload.

3. Prepare eligible Coordinators for National Certification:
   One eligible Coordinator and our Clinical Director were both certified. We will have new team members certified next year. Coordinators are eligible for certification after one year of practice and intensive coordinator training occurs.

4. Seek linkages for children's services:
   Only one formal linkage agreement has been obtained with a children's services provider. Over the course of the year of new program development in the area of child services, we have been building relationships with the regional providers of child services that will lay the groundwork for adding more agreements. This will continue to be an important action item for the Director.

5. Expand training for children's services:
   Extensive outreach and training for families and service providers has been provided over the course FY 2016 as NC START West began serving children. This will be an ongoing process.

6. Implement START Therapeutic Coaching:
   START Therapeutic Coaching services are just underway. The program is fully staffed and we have completed training for the coaches in our region. We will begin supporting children and their families in our region during this next fiscal year.

7. Decrease adult waitlist:
   Efforts to decrease the adult waitlist have been ongoing. There was a shift in focus over the past year to roll out children's services. In addition to individuals still on the waitlist, new adult referrals continue at a steady pace. A critical goal for FY 2018 will be to reduce and eliminate the waitlist and to increase START Coordinator caseload sizes. VAYA funded a position to decrease their adult waitlist, which will be helpful in addressing this need.

Findings

The following report provides an analysis of enrollment, demographic and service outcome data for the NC START West 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 West are based on data entered into the START Information Reporting System (SIRS) by program staff. The NC START West 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 West during FY17 (N=160). 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.

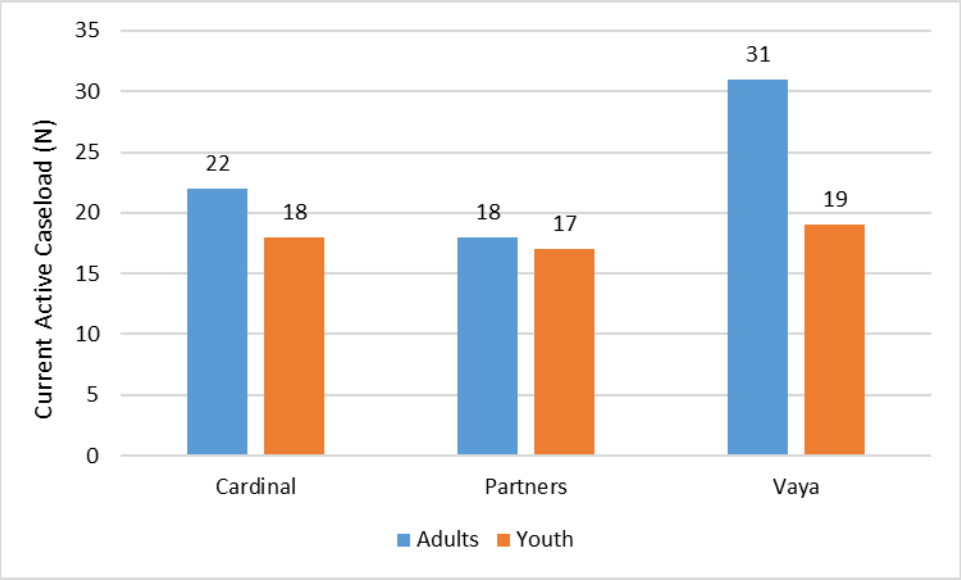
Table I.A: Enrollment Trends: Adults (21+ years old)

	FY17
Total Caseload at Beginning of Reporting Period	89
Individuals **Enrolled** During Reporting Period	6
Individuals **Inactivated** During Reporting Period	24
Total Caseload at End of Reporting Period	71
Individuals Served During Reporting Period	**95**
Percentage of Total Caseload	**59%**

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

	FY17
Total Caseload at Beginning of Reporting Period	3
Individuals **Enrolled** During Reporting Period	62
Individuals **Inactivated** During Reporting Period	11
Total Caseload at End of Reporting Period	54
Individuals Served During Reporting Period	**65**
Percentage of Total Caseload	**41%**

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 19 months for adults, which is slightly higher than the National average of 12 – 18 months. There were not enough youth inactivated for stable functioning to report on this variable.

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

Variable	**Adults**	**Youth**
N	24	11
Reason for Inactivity (%)		
Stable functioning	54%	18%
Moved out of START region	4%	18%
No longer requesting services	17%	9%
Unable to contact	17%	36%
Long-term placement	4%	18%
Too medically fragile	4%	0%

Table I.D: Source of Enrollment to START

Variable	**Adults**	**Youth**
N	6	62
Source of Enrollment (%)		
Service Coordinator	50%	98%
Mobile Crisis	17%	0%
Hospital emergency department	17%	0%
Other	17%	2%

Table I.E: Reasons for enrollment

Variable	**Adults**	**Youth**
N	6	62
Most Common Reasons for Enrollment (%)		
Aggression	50%	85%
Family Needs Assistance	33%	77%
Risk of losing placement	0%	8%
Mental Health Symptoms	33%	15%
Suicidality	17%	6%
Self-Injurious Behavior	17%	10%
Sexualized behavior	0%	18%
Leaving unexpectedly	17%	16%
Transition from hospital	0%	5%

Summary

- NC START West services to children have steadily expanded, with the expansion to children services beginning in August 2016. All Children's START Coordination referrals are initiated through the LME/MCO's. This has proven to be an effective process and a positive collaboration.
- NC START West enrolled a large number of children in FY17 as the children's services component was being developed and launched. This resulted in some slowing of the enrollment of adults.
- Service Coordination is not provided to all eligible individuals through the MCOs. This support is also provided by clinical homes such as residential programs or enhanced clinical service providers. During FY17 one adult referral was from a community provider and two others came directly from emergency services.
- 24 adults were inactivated with NC START West, half of whom were determined to have been stable for a period of at least six months.
- Some adult referrals are made by Emergency service providers or MCOs, however, families/guardians and or providers are not always ready to fully engage in START services. This results in inactivation of cases where after an intake process has been completed, guardians indicate that they do not want additional services and situations in which START Coordinators are unsuccessful in their efforts at assertive outreach.
- When an individual, family, guardian and/or provider cannot be contacted in spite of repeated outreach efforts over a period of several months, NC START West inactivates the case.
- The data show that half of all adults and the majority of youth are referred with aggression as a primary concern, consistent with national data trends.
- A significant proportion of enrolled children live with family members and family needing assistance was the second most frequently reported reason for referral to START services.

Goals

- NC START West will collaborate with the MCOs to identify at risk youth as early as possible prior to experiencing major crises, to continuously work on promoting less tertiary and more secondary (prevention oriented) interventions for this population.
- NC START West will collaborate with MCOs and agencies serving adults with IDD in our region to focus on identifying adults at risk and securing referrals prior to the need for Mobile Crisis and Emergency Department services.

- NC START West will conduct a review of the adult waitlist to clarify individuals who would currently benefit from START enrollment. A key goal is to eliminate the adult waist list by enrolling more adults and increasing caseload sizes during FY 2018.

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=160) 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 West**	**FY17: Other START Programs**	**FY17: NC West**	**FY17: Other START Programs**
N	95	1705	65	809
Age (Mean)	34	35	15	16
Gender (% male)	57%	60%	77%	76%
Level of Intellectual Disability (%)				
No ID/Borderline	3%	8%	3%	14%
Mild	51%	47%	54%	38%
Moderate	33%	26%	29%	26%
Severe-Profound	8%	9%	3%	7%
Level Unspecified	4%	6%	9%	13%
Missing	1%	3%	2%	3%
Living Situation (%)				
Family	39%	35%	**62%**	83%
AFL/Foster Care	15%	9%	9%	2%
Group Home and Community ICF/DD	27%	30%	8%	6%
Independent/Supported living	2%	13%	0%	2%
Psych. Hospital/IDD Center	**11%**	3%	6%	2%
Other (Jail, Homeless, "Other")	6%	7%	**15%**	3%
Missing	0%	3%	0%	1%
Funding Source (%)				
IDD Waiver	47%	49%	18%	40%
Medicaid	52%	37%	80%	45%
Medicare	0%	1%	0%	0%
Private Insurance	0%	2%	2%	4%
State funds	1%	2%	0%	2%
Missing	0%	9%	0%	9%

Summary

- NC START West serves a larger number of individuals with moderate to severe IDD than is found in population samples of people with IDD. This suggests increased complexity of needs, beyond behavioral health. Approximately half of our enrollees have mild cognitive impairments. NC START West data on levels of intellectual disability is consistent with national START data.
- A number of both adult and children enrollees are not receiving waiver services, which can restrict opportunities for much needed supports and services. The percentage of NC START West enrolled adults receiving waiver supports is similar to that of other START programs. At the time of referral, some adults were in long-term stays at psychiatric facilities.
- The percentage of NC START West enrolled children and youth receiving waiver supports is much lower than the average reported across START programs. This contribute to the challenges families experience trying to keep children at home. Both high rates of aggressive behaviors and high levels of need for family supports were identified in our data analysis.
- A number of youth referred to NC START West have experienced frequent psychiatric hospitalizations, residential instability and/or frequent involvement with law enforcement. At time of intake, approximately 20% of youth were living in Psychiatric Residential Treatment Facilities and a few were incarcerated.

Goals

- Further study of the impact of enrollment in START services on the rate of placement loss and moves into more restrictive settings for both adults and children is needed.
- Based on findings to date, a number of changes in practice may be needed to improve outcomes including improved efforts at earlier identification of at-risk individuals, more systemic education and training and increasing outreach interventions to prevent occurrences such as incarceration, hospitalization and loss of placement with family or other community care settings.

Mental 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 DSM-5 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 West	FY17: Other START Programs	FY17: NC West	FY17: Other START Programs
N	95	1705	65	809
Mental Health Conditions (%)				
At least 1 diagnosis	95%	84%	**98%**	78%
Mean Diagnoses	1.9	2.0	2.3	2.1

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

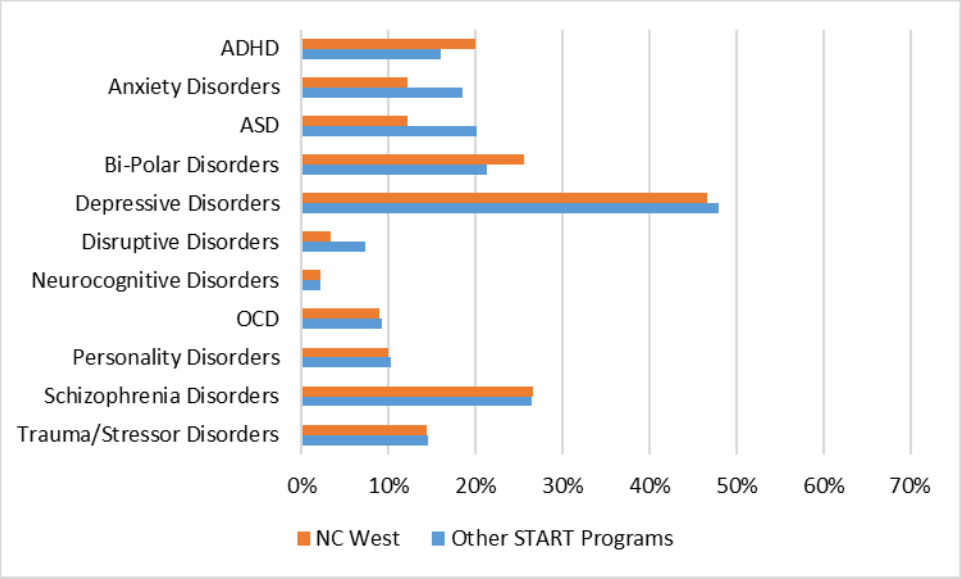
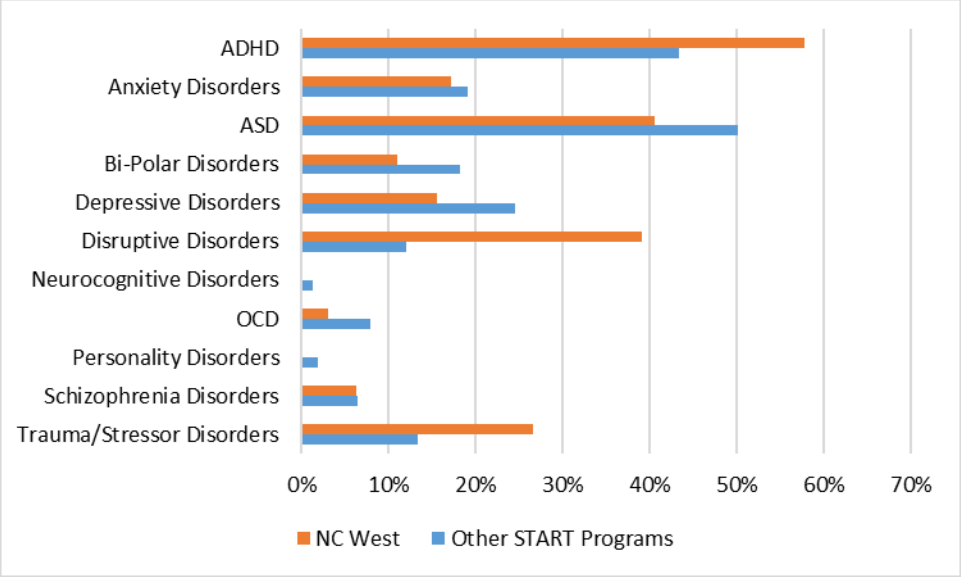


Figure II.B: Frequency of most common mental health conditions for enrolled youth



Summary

- The diagnostic data reported for NC START West enrolled adults is consistent with national START data.
- For NC START West enrolled youth, it is notable that ADHD and Trauma/Stressor Disorders are diagnosed with greater frequency than seen in the national data. ADHD has been reported to occur more frequently in youth with an ASD, and in some of the research regarding children with IDD as well. However, these youth tend to have lower rates of response to stimulant therapies. This supports the possibility that there may be a tendency to over-diagnose ADHD in this group. This may be related to a lack of understanding of the impact of neurodevelopmental challenges on expressions of distress and anxiety. The higher rate of identified trauma related disorders is positive in the sense that for many programs, there is much concern that these challenges are missed or under-appreciated.
- The observed elevated rate of diagnoses of Disruptive Behavior Disorders may relate to DSM-5 diagnostic changes that resulted in the addition of a new diagnostic category of Disruptive Mood Dysregulation Disorder (DMDD). It is unclear if this diagnosis is being made correctly, and there is concern that anxiety disorders may often be missed. In well controlled studies, anxiety disorders are the most common psychiatric diagnoses in clinically referred populations of children with and without IDD.
- The number of children diagnosed with an ASD is less than that reported for other START programs (about 40% versus 50%). Some of the youth diagnosed with Disruptive Behavior Disorders and ADHD may in fact include missed cases of ASD. In more rural areas of the NC START West region, availability of appropriate screening and assessment for the presence of an ASD may be limited.
- It is unclear why our data indicates a higher frequency of multiple mental health diagnoses at time of referral as compared to the national average.

Goals

- More training will be provided regarding the effects of executive function deficits and unique neurodevelopmental challenges on differential diagnostic considerations, with reference to emerging trends in diagnostic assessment.

- Members of the NC START West team will be receiving training from the National Center for START services that address differential diagnosis for psychiatric syndromes within study groups that prepare for coordinator certification and in other study group forums.
- Internal clinical case reviews will be focused in updating NC START West staff skills in identifying symptoms and syndromes, consistent with emerging research and new classification systems.

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 West**	**FY17: Other START Programs**	**FY17: NC West**	**FY17: Other START Programs**
N	95	1705	65	809
Chronic Medical Conditions (%)				
At least 1 diagnosis	68%	66%	46%	51%
Mean Diagnoses	2.4	2.1	2.3	1.6

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

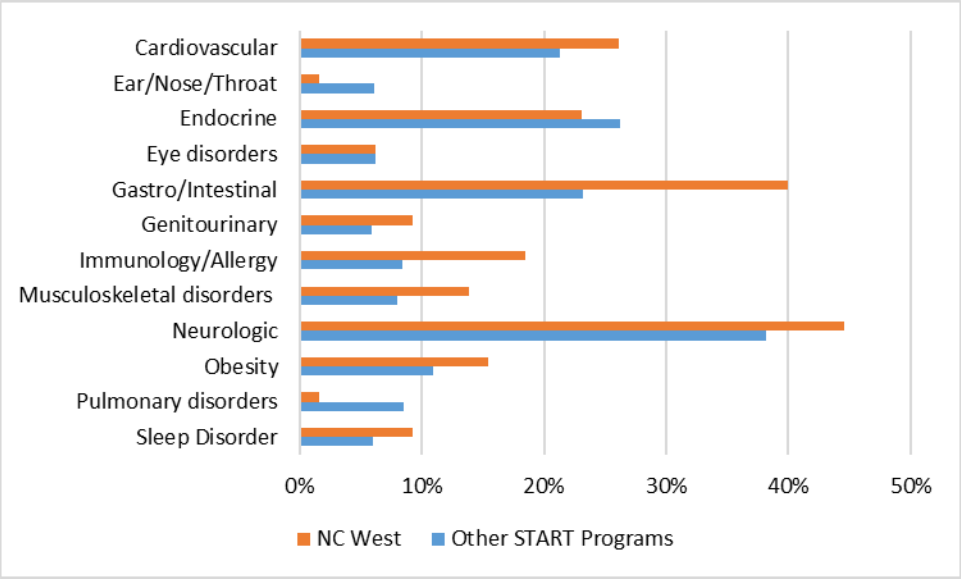
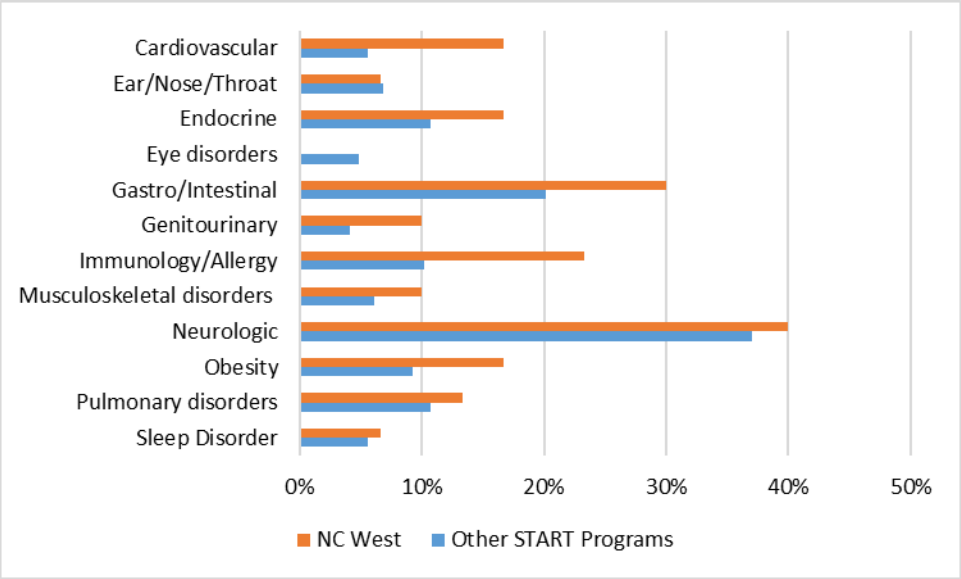


Figure II.D: Frequency of most common chronic medical conditions for enrolled youth



Summary

- Rates for a number of health-related conditions are higher in the NC West region than reported in other START programs. This may be related to multiple factors including more limited access to health services in rural areas. This has been noted in many communities in which healthcare disparities have been studied among people with ID/D.
- There may be more health related conditions secondary to lifestyles common to or even unique to the region. It may be that similar findings would apply to neurotypical individuals living in the region.
- In addition to the above, service providers in the NC START West region are sensitive to the medical needs of the individuals supported, and may be more likely than providers in other areas to aggressively work to identify health concerns.
- NC START West Coordinators and other team members have been working to promote awareness through training, and are recording more accurate data regarding health concerns in SIRS. They have been trained to look for signs and symptoms, and to raise questions regarding alterations in mood and behavior that may be linked to missed medical problems causing distress related functional changes.

Goals

- Give the high rates of medical comorbidity, future system wide and individual team trainings regarding the nature and likely impact of these comorbidities will be planned and provided during FY 2018.
- NC START West's Medical Director will be reviewing cases and will continue to help identify health concerns that may be impacting enrollees.

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	95	65
Psychiatric Hospitalizations		
Prior to enrollment, N (%)	37%	46%
Mean (range)	1.8 (1-8)	1.7 (1-5)
Percent with Multiple Admissions	31%	37%
During START, N (%)	**16%**	**8%**
Mean (range)	2.5 (1-8)	1.8 (1-3)
Percent with Multiple Admissions	60%	60%
Emergency Department Visits		
Prior to enrollment, N (%)	53%	46%
Mean (range)	2.6 (1-15)	2.0 (1-9)
Percent with Multiple Visits	47%	47%
During START, N (%)	**28%**	**23%**
Mean (range)	2.0 (1-7)	1.5 (1-4)
Percent with Multiple Visits	52%	33%

Summary

- Both children and adults served by NC START West experienced significant reductions in Emergency Department use and psychiatric hospitalization between pre- and post-enrollment in START. The significant reduction in the use of psychiatric hospitalizations and emergency department visits has been facilitated through the use of a team approach in creating effective Cross System Crisis Prevention and Intervention Plans, consistent outreach to families and teams, and through encouraging a proactive approach to crisis prevention.
- While the number of psychiatric hospitalizations and emergency department usage for NC START West enrollees are higher than the average, we continue to see a reduction by maintaining fidelity to the model. Emergency Service utilization is a trend that is hard to break. Continued outreach and training and being present for community teams are critical.

Goals

- Demographic and clinical trends for individuals with higher emergency service utilization will be reviewed and analyzed. Findings will be used to guide community training and outreach efforts, as well as other practice changes aimed at improving outcomes.

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 West 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 West 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	54	100
Community-based training	8	10
Host Advisory Council Meeting	6	4
Provided training to day provider	9	4
Provided training to emergency services	4	3
Provided training to family	14	1
Provided training to other	62	9
Provided training to physician/medical personnel	6	2
Provided training to residential provider	19	5
Provided training to school	1	
Provided training to state facilities (state hospitals, developmental centers)	1	1

Provided training to therapist/mental health providers	4	2
Time spent on affiliation and linkage agreements	2	1
Transition Support/Planning-Developmental Center	2	
Transition Support/Planning-Psychiatric Hospital	3	5
Total Episodes	195	147
Linkage/Collaboration Agreements	13	15
Clinical Education Team (CET)	6	7

The following is a list of some of the training topics offered to the community as part of the primary services provided by NC START West during FY17.

- Executive Functioning
- Schizoaffective Disorder
- Borderline Personality Disorder
- Autism Spectrum Disorder
- Sensory Integration Dysfunction
- Trauma and IDD
- Noonan Syndrome
- Tertiary Care Model
- Disruptive Mood Dysregulation Disorder
- START Resources
- START Model
- Multiple Individual Specific Trainings

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

- With the expansion into children's services, NC West's clinical focus has been on development of child services. The training focus also shifted somewhat and there has been a more concentrated effort to provide training for the provision of lifespan model services.
- An assistant Clinical Director position was added to focus on maximizing therapeutic activities at our new Center. Internal staff trainings occurred as a result.
- Inaccurate data entry may also have been a factor in reflecting a lower frequency in training episodes.

Goals

- The frequency and variety of locations for Clinical Education Team trainings across our region will be increased during FY 2018. In order to maintain program certification requirements, the program has to provide 10-12 CETs in the coming year.
- Extra efforts will be made this FY to increase the number and scope of Linkage agreements and to identify training needs of local stakeholders serving children.

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

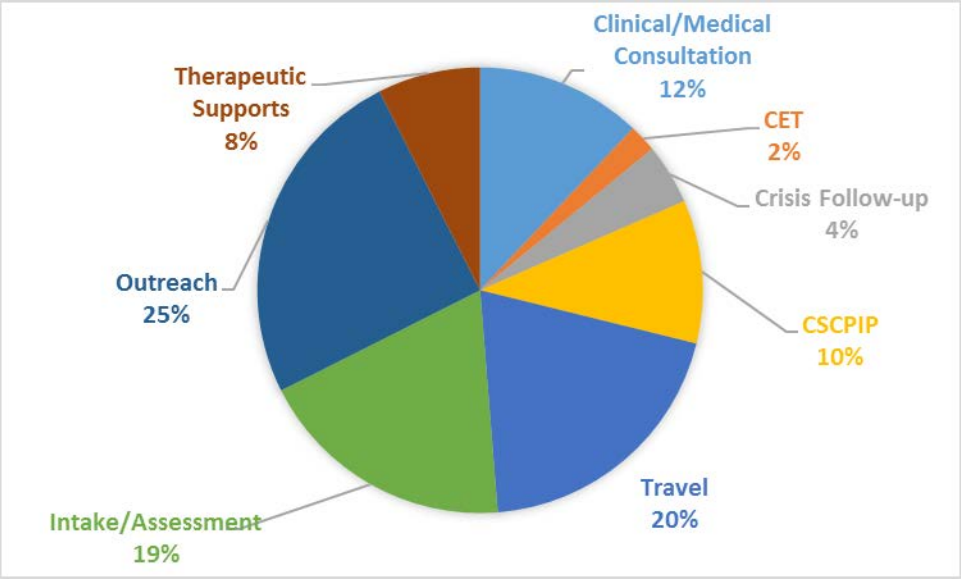


Figure IV.B: Planned Service Utilization Trends (Percent of Adults)

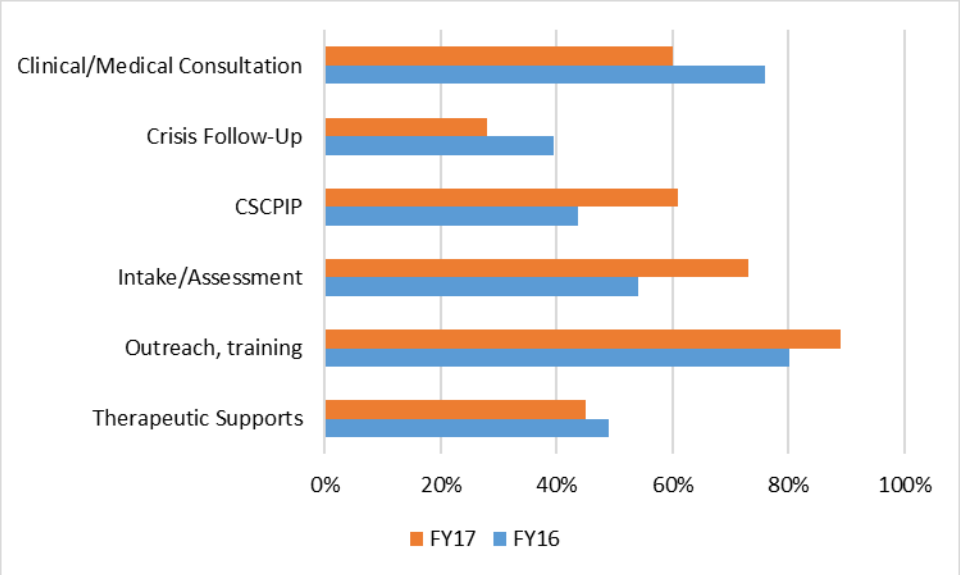
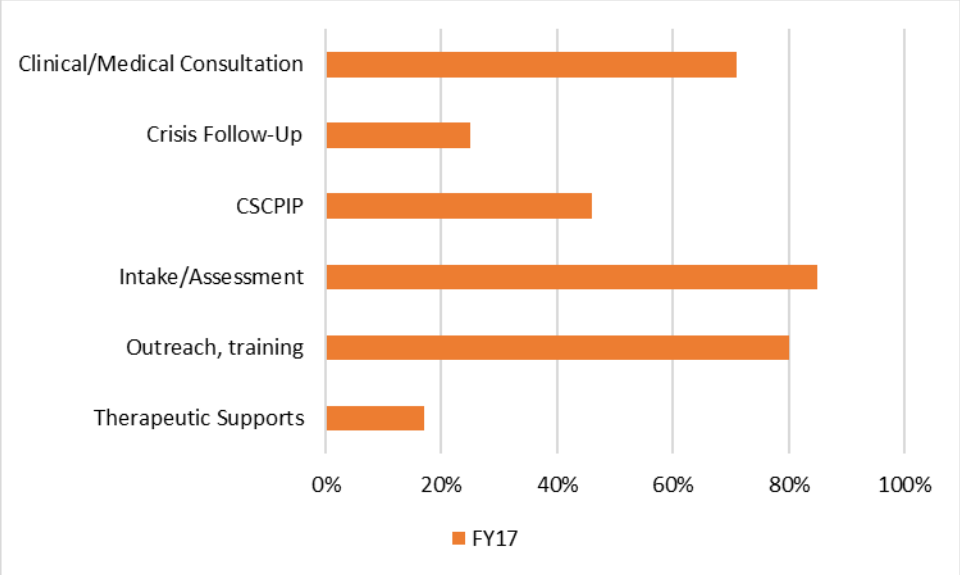


Figure IV.C: Planned Service Utilization (Percent of Youth)



Summary

- A relative increase in the proportion of time spent on outreach and crisis prevention planning (prevention oriented activities) versus time spent on crisis work, was reported for adults during FY17.
- A significant proportion of time spent serving children during FY17 was focused on Intakes, Clinical Consultation and Outreach.

Goals

- The NC START West team will maintain fidelity to the START model in the provision and documentation of START services.

START Intake and Assessment

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

The Aberrant Behavior Checklist (ABC), developed by Aman and Singh, is completed for all enrolled individuals at the time of intake and every 6 months thereafter until the enrolled individual is stabilized. Research of ABC scores for individuals receiving START services indicates that the lethargy and irritability subscales are strong predictors of emergency service use.

The Recent Stressors Questionnaire (RSQ), developed by Laurie Charlot, LCSW, Ph.D. is also completed at time of intake and as part of the emergency assessment process. The RSQ is a valuable assessment tool and assists the coordinator with gathering important biopsychosocial information about the individual and his/her crisis experience. 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	88%	86%
Aberrant Behavior Checklist (ABC)	88%	91%
Recent Stressors Questionnaire (RSQ)	89%	92%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	74%	76%

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=98). 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=98), results show that average scores decreased in each subscale as shown in Table IV.

Table IV.C: ABC Analysis

		Mean Score			
NC West (N=98)	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one-tail**
Hyperactivity/Noncompliance	69%	17.62	13.11	4.62	0.00
Inappropriate Speech	36%	3.29	3.01	.84	NS
Irritability/Agitation	66%	19.07	15.20	3.77	0.00
Lethargy/Social Withdrawal	55%	8.94	7.12	2.37	0.01
Stereotypic Behavior	37%	2.85	2.42	1.27	NS

Alpha= 0.05

Summary:

- The completion rate for Cross Systems Crisis Plans was inadequate for the enrollment period, but this issue will be aggressively addressed in FY18.
- Other assessments tools were completed at higher rates (close to 90%) and in accordance with START expectations.
- ABC Hyperactivity/Noncompliance, Irritability/Agitation and Lethargy/Social Withdrawal scores showed significant improvement in follow up administrations. This is consistent with outcome based research that examines the impact of START services.

Goals:

- All NC START West enrollees will have a Cross System Crisis Plan developed in a timely fashion, in accordance with START requirements.
- All NC START enrollees will have completed assessment tools that are required at intake, and other tools as indicated.
- Required SIRS documentation will be done in a timely manner.

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	47	**29**	**17**
Total number of crisis contacts	91	**67**	**27**
Average number of contacts	1.9	2.3	1.6
Number of individuals with more than 1 Emergency/Crisis services	18	16	7
Percent of individuals with more than 1 Emergency/Crisis services	38%	55%	41%

Table IV.E: Type of Crisis Response

	FY16		FY17	
Type of Response	N	%	N	%
In-Person	53	58%	74	79%
Phone consultation only	38	42%	20	21%
Total Contacts	**91**	**100%**	**94**	**100%**

Table IV.F: Outcome of Crisis Contact

	FY16		FY17	
Outcome of crisis contact	**N**	**%**	**N**	**%**
Maintain current setting	29	32%	31	33%
Psychiatric hospital admission	9	10%	10	11%
Emergency Department	1	1%	0	0%
Emergency Department hold	10	11%	11	12%
Referral out for services	4	4%	7	7%
Crisis Stabilization	1	1%	13	14%
Medical Evaluation/Admission	0	0%	0	0
START Emergency RC admission	24	26%	15	16%
START Planned RC stay scheduled	9	10%	2	2%
ICF Placement			1	1%
Unreported	4	4%	4	4%
Total Crisis Contacts	**91**	**100%**	**94**	**100%**

Table IV.G: Reason for Emergency Department Hold

Reason for ED Hold	FY16 (N)	FY17 (N)
Medical Evaluation	1	4
No hospital beds available	3	4
No placement available	6	2
Total	**10**	**10**

Summary:

- There is ongoing concern that individuals seen in the Emergency Department are often unable to go home (only 33% maintained current setting). When possible and when indicated, hospitalization is diverted by making use of the START Resource Center or a crisis stabilization bed. A subset of individuals are hospitalized and should receive this form of care.
- A number of adults experience holds in the Emergency Departments. This is typically due to lack of hospital bed capacity, unavailability to respite crisis beds in the community and/or discontinuation of previous community residential placement.
- The frequency of in-person crisis response increased from FY 2016 to FY 2017, which is a desired trend.
- The number of crisis calls reported in SIRS is lower than anticipated. This is likely a reflection of under-reporting.
- An important goal of START crisis intervention is to prevent the need for more intensive emergency service utilization, such as psychiatric hospital admissions, whenever clinically appropriate. While note noted in the tables above, it is important to note that in FY17, 40% (or 38 people) of individuals using START crisis intervention services were able to be diverted from the hospital as a result of those services. (Information taken from SIRS database, not shown here in tables)

Goals:

- NC START West leadership team will review individuals placed on Emergency Department holds, and individuals who are not able to return to their residential settings. A better understanding of trends can guide teams in addressing the barriers to less restrictive outcomes for these individuals.
- A new system of tracking crisis calls will be developed to ensure accurate and timely data entry.

Section V: START Therapeutic Resource Center Services

Table V.A: Planned Resource Center Stays

Planned Resource Center Stays	FY16	FY17
Number of individuals	48	41
Total number of stays	144	144
Range of days	1 to 11	1 to 9
Avg Length of Stay (Days)	4	3.5
Total time spent in resource center (in days)	562	510
Number of individuals with more than 1 Resource Center - Planned	33	20
Percent of individuals with more than 1 Resource Center - Planned	69%	73%
Occupancy Rate (2 beds X 365 days): 730 days	77%	70%

Table V.B: Emergency Resource Center Stays

Emergency Resource Center Stays	FY16	FY17
Number of individuals	26	18
Total number of stays	34	30
Range of days	2 to 30	2 to 30
Avg Length of Stay (Days)	17	20
Total time spent in resource center (in days)	576	589
Number of individuals with more than 1 Resource Center - Emergency	4	7
Percent of individuals with more than 1 Resource Center - Emergency	15%	39%
Occupancy Rate (2 beds X 365 days): 730 days	79%	81%

Summary

- There has been an increase in the number of individuals using multiple Emergency Resource Center stays. More in-depth assessment, careful transition planning and intensive follow up is needed to enhance the capacity of our system in meeting the needs of this complex population. It is also important to continue reviews of the Cross Systems Crisis Plans to ensure the providers are utilizing these plans and if, in fact, they are effective and useful.
- The NC START West Resource Center continues to be an important resource for the community in reducing the use of emergency services. Each emergency stay is viewed from a systems approach; outreach is provided and training is offered to community providers to strengthen the capacity for responding successfully to crisis events.

Goals

- NC START West will increase training and collaboration efforts with families and community agencies that request frequent use of Resource Center emergency beds.

Conclusions and Goals for FY18

Conclusion

NC START West has experienced much change and growth during the past year. Our team more than doubled in size, with expansion into children's services. The next steps include an active Therapeutic Coaching component that operates at full capacity. The Resource Center will benefit from additional clinical presence and program development.

Data showed that enrollment in START services was associated with significant pre to post START reductions in use of emergency services as well as reductions in reported psychopathologic symptoms. Individuals enrolled in the START program were provided with an array of services, with major efforts in the areas of outreach and clinical consultation. There has been ongoing intense work in the area of education and training to increase the skills and capacities of individual caregivers, teams and agencies working with individuals with ID/D who have complex behavioral health needs.

There will be a focus on formalizing linkages and enhancing community outreach in the coming FY. These are critical components of START that contribute to expansions in training and the provision of clinical supports. Case load sizes will be increased.

The SIRS data collection system has been instrumental in guiding efforts to provide evidence informed care and to guide practice. Maintaining fidelity to the START model is essential and must be carefully attended to during times of change.

Goals for Fiscal Year 2018

1. Collaborate with the MCOs to identify at risk youth and adults to continuously work on promoting less emergency and more prevention oriented interventions.
2. Provide more systemic education and training and increasing outreach interventions to prevent occurrences such as incarceration, hospitalization and loss of placement with family or other community care settings.
3. Conduct a review of the adult waitlist to clarify individuals who would currently benefit from START enrollment. A key goal is to eliminate the adult waist list by enrolling more adults and increasing START Coordinator caseload sizes during FY 2018.
4. More training will be provided regarding the effects of executive function deficits and unique neurodevelopmental challenges on differential diagnostic considerations, with reference to emerging trends in diagnostic assessment.
5. Internal clinical case reviews will be focused in updating NC START West staff skills in identifying symptoms and syndromes, consistent with emerging research and new classification systems.
6. Demographic and clinical trends for individuals with higher emergency service utilization will be reviewed and analyzed. Findings will be used to guide community training and outreach efforts, as well as other practice changes aimed at improving outcomes.

7. The frequency and variety of locations for Clinical Education Team trainings across our region will be increased during FY 2018.
8. Extra efforts will be made this FY to increase the number and scope of Linkage agreements and to identify training needs of local stakeholders serving children.
9. The NC START West team will maintain fidelity to the START model in the provision and timely documentation of all assessment data and START services.
10. A new system of tracking crisis calls will be developed to ensure accurate and timely data entry.
11. NC START West will increase training and collaboration efforts with families and community agencies that request frequent use of Resource Center emergency beds. There will be additional emphasis on discharge planning and outreach to caregivers to lower the rate of recidivism for crisis stays at the Resource Center.
12. The Therapeutic Coaching Program will be fully implemented with a goal to maintain this service at full capacity. This service will promote improved capacity to further reduce emergency service use.