NC START

Systemic • Therapeutic • Assessment • Resources • Treatment

NC START Annual Report

Fiscal Year 2021

Prepared for

North Carolina Department of Health and Human Services

and

The NC START Programs

Prepared by

The Center for START Services

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START (Systemic, Therapeutic, Assessment, Resources, & Treatment) is a cross-systems crisis prevention and intervention model of evidence-based practices and supports to promote the well-being of individuals with intellectual/developmental disabilities (IDD) and mental health service 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 IDD and mental health needs in the community.

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Introduction

This report is a summary of service outcomes from NC START programs during fiscal year 2021 (July 1, 2020-June 30, 2021). START is a fidelity-based model, and the Center for START Services provides needed resources and training to develop and implement START services in partnership with provider agencies and the North Carolina Department of Health and Human Services (DHHS). The report includes general information about the individuals served by NC START as well as separate sections detailing specific outcomes and information for each of the three regional programs. The data in this report comes from information entered by program staff into the START Information Reporting System (SIRS).

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NC START Central Program

NC START East Program

NC START West Program

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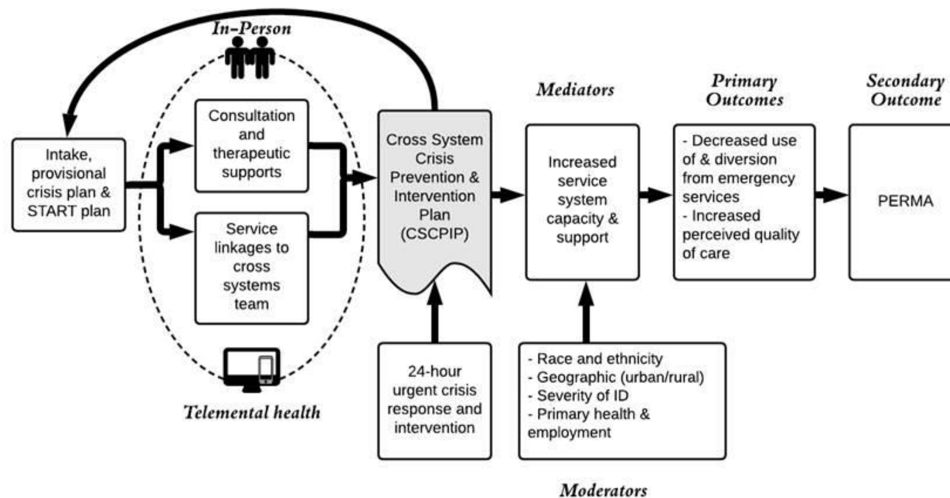
Section I. Background

First developed by Dr. Joan B. Beasley in 1988, START was cited as a best practice in the US Surgeon General's Report (2002) and more recently presented to the National Academy of Sciences, Engineering and Medicine (2016). Studies spanning over 30 years of START services have found significant reduction in crisis service use, emergency department visits, and psychiatric hospitalizations. [1,2]

As shown in the figure below, START programs provide mental health assessment and 24-hour crisis response, START coordination and coaching/support, along with training and systems linkages to address the mental health needs of people with IDD and their families. START crisis prevention and intervention services are patient-centered and engage service recipients with IDD-MH in treatment, including those with significant delays in cognitive, communication, and social functions. START services significantly reduce emergency mental health service use, and caregivers report high service satisfaction.



National START Program Certification

The Center for START Services (CSS) provides in-person and web-based training, technical assistance, planning, and case consultation to implement the START model. Ongoing technical assistance includes close collaboration with stakeholders, quality reviews of START methods, and evaluation through data entered into the START Information Reporting System (SIRS). The goal of CSS is to foster the successful development and implementation of the START model and to assess efficacy and quality of fit in each location where the model is implemented. The goal is for each START team to be fully certified within three years and to maintain engagement with the National START Network. All of the NC START programs are fully certified, lifespan programs since 2015.

Training, consultation, and quality assurance monitoring provided by CSS to the NC START programs include:

- Triage participation to assist with proactive crisis response and intervention
- In-person consultation visits
- Leadership training and development
- Clinical team coaching, training, and team development

[1] Kalb, LG, Beasley, J., Caoili, A., & Klein, A. (2019). Evaluation of the START crisis intervention and prevention program. *American Journal of Intellectual and Developmental Disabilities,* 124(1), 25-34.

[2] Beasley, J., Kalb, L., & Klein, A. (2018) Improving Mental Health Outcomes for Individuals with Intellectual Disability through the Iowa START (I-START) Program. *Journal of Mental Health Research in Intellectual Disabilities, 11*(4), 287-300.

- Attendance and participation in Clinical Education Team Meetings, Advisory Council meetings, and other regionally specific outreach efforts
- North Carolina specific training workshops
- Program evaluation (monthly, quarterly, and annual reports)
- SIRS database training and technical assistance
- Clinical record reviews
- Coordinator training and certification
- Therapeutic Coaching training groups
- START National On-Line Training Series
- START Practice Improvement Groups
- START National Training Institute

START Response to the COVID-19 Pandemic

Regardless of START enrollment status, people with IDD are at high risk of stress and mental health related distress associated with the COVID-19 pandemic. Without maintaining appropriate supports for this vulnerable group, they are at risk for increased mental health crises that affect their safety and the safety of their families and heightens the human and financial costs to the broader community. In collaboration with the Center for START Services and the national START Network, the NC START programs are committed to supporting the IDD community through this public health crisis.

During the COVID-19 shutdown, the Center for START Services rapidly and strategically initiated the development of telehealth crisis support protocols across the START network. Telehealth is identified as an evidence-based method to delivering mental health services and supports on virtual or remote platforms[3]. A series of virtual meetings with START program directors, administrators, funders, and other stakeholders were held to review the telehealth protocols, and revisions to the SIRS database were made to accurately capture telehealth service delivery by START programs.

The START Network collaborated and provided accessible information and training about COVID-19, therapeutic supports, clinical services, and crisis response using telehealth methods.

In addition to the modification of protocols for START programs, CSS also initiated the development of a *COVID-19 Resources* page on the CSS Website, which was used by START programs and community stakeholders nationwide. The National START Emergency Management Committee was convened in response to the pandemic as well. The committee's initial objective was to address immediate gaps in emergency response to COVID-19, and three task forces were developed to address the present needs of service users, families, and communities across the country as a result of COVID. These task forces were: 1) mobile START crisis response; 2) therapeutic interventions and 3) transition planning.

The National START Emergency Management Committee

The Emergency Management Committee is a national forum developed by and with START network partners and is designed to provide comprehensive, interdisciplinary support to START service users, families, providers, and START teams in response to emergency circumstances. The EMC is committed to developing a framework for rapid mobilization across the START network, building on linkages across the START network, available resources, expertise, innovation, and collective intelligence. The goal is to establish a "think tank" to develop, review, and evaluate practices designed to support START service users during times of local/national crisis. The committee addresses macro level (community-level) crises as well as assists START network providers in addressing micro level (individualized) needs.

One example of the work of the Emergency Management Committee beyond the COVID-19 pandemic was the rapid response to the CA wildfires. It was brought to the attention of the committee that many across the state of California, including START staff and service recipients, were forced to evacuate their homes. Emergency shelters needed resources and training materials to aid in

[3] Totten AM, Womack DM, Eden KB, et al. (June 2016). Telehealth: Mapping the Evidence for Patient Outcomes from Systematic Reviews (Technical Brief 26) [Internet]. Rockville (MD): Agency for Healthcare Research and Quality.

the effective support of persons with IDD. Members of the committee came together and developed brief information sheets specific to supporting persons with IDD in crisis situations that were distributed to CA regional centers and shelters.

Information and resources developed by the National START Emergency Management Committee can be found in the *Resources* area of the Center for START Services website https://www.centerforstartservices.org/Resources/EMC.

Section II. NC START Highlights

Despite the effects of COVID-19 on their communities, the NC START programs provided services and supports to over 700 persons with IDD-MH across the state in FY2021. The following are statewide highlights from throughout the year. For program specific team updates and highlights, please refer to each program's section below.

Transition to telehealth and virtual service delivery: When COVID-19 shelter in place orders were implemented, NC START program staff quickly pivoted to new methods of service delivery. To support those enrolled in NC START, staff shared plain language materials and provided resources and training about COVID-19. In addition, all NC START programs began providing telehealth services, which continued throughout FY2021. Additional fields in SIRS were added to track telehealth outreach, therapeutic coaching visits, and crisis follow-up. The percent of individuals who received telehealth services in each region is included in the program specific sections below. While preliminary findings show positive outcomes associated with telehealth, additional study is needed. The Center for START Services looks forward to continuing to collaborate with the NC START programs and DHHS in evaluating telehealth START services to inform ongoing best practices.

Continued linkage and relationship building: Clinical Education Trainings (CETs) are an important facet to the capacity building efforts of NC START. These in-depth case studies allow for interactive learning and collaboration in a multi-disciplinary format. During FY21, NC START teams continued to offer CETs in a virtual format and conducted over 30 of these specialized consultations across the state, averaging 33 attendants per event.

In addition to training, linkages continue to be a vital piece of NC START's community capacity building. Each program has numerous linkage agreements with partners in their region (see Appendix B). These linkages allow for collaboration and connection with a variety of partners including mental health and IDD providers as well as transportation, recreation, healthcare, and educational resources. NC START teams also link with emergency service providers such as law enforcement, fire departments, and hospitals to help facilitate effective collaboration during crisis events and prevent unnecessary utilization of these services. Advisory council members and community partners work with NC START teams to engage the community in training initiatives to share information and best practices in IDD-MH. In FY21, NC START programs provided over 780 hours of community training to diverse audiences on a variety of topics using both in-person and virtual platforms.

NC START Cross Program Collaboration: Since NC START operations began, over 200 individuals have been served in multiple NC START regions. NC START staff collaborate across regions to ensure that START services can be continued without interruption when a move takes place. While region transfers (n=5) were drastically reduced in FY2021 due to shelter-in-place orders, over the last three years over 65 individuals have received services in at least two different regions.

Reduction in Emergency Service Use: Overall, there was a reduction in emergency service use for individuals enrolled in the NC START program with decreases in both ED and psychiatric hospitalization rates pre- to post-enrollment. Data also show a reduction in mental health symptoms as measured by the Aberrant Behavior Checklist.

NC START Central

NC START Central served a total of 279 people with IDD in fiscal year 2021. Program leadership also identified and worked to address barriers to stability for individuals who have been active with START for an extended period of time. The program continues to work with their partners to build capacity to serve persons with IDD within the region. They established a partnership with Duke Autism Clinic to facilitate monthly consults for "specialized high needs cases". This has recently expanded to the East and West regions, making the clinic a statewide initiative.

The NC START Central team worked throughout the pandemic and resulting stay-at-home orders to continue to support individuals, families, and providers. They implemented telehealth therapeutic coaching groups to promote PERMA+ for children and transition age youth. Coaches developed an eight (8) week curriculum designed to address specific therapeutic areas. These included but are not limited to life skills, leisure, health and wellness, and gender specific groups. They also conducted daily telehealth resource center groups with similar goals for adults who typically access planned center-based stays.

In addition to a shift in methods of START service delivery, the NC Central program offered technology device loans for individuals who did not have access. This allowed for full engagement in telehealth therapeutic supports that would not otherwise have been available. The program also developed the Lunchbox training series that provides hands-on community training along with tangible resources to families and providers. Training topics focused on promoting PERMA+, biopsychosocial approaches, and sensory needs for individuals with limited resources during COVID-19.

NC Central took advantage of the virtual environment to increase reach to a broader audience for training and CETs. This resulted in higher attendance this year when compared to previous years. The program also has a strong and active Advisory Council, comprised of representatives from DHHS, partner managed care organizations, and community provider agencies. The support of the Advisory Council was paramount over the last year and focused on community and individual needs related to COVID-19.

NC START East

The NC START East program continues to maintain national START Program Certification and has a strong presence in their region. This year, the program introduced direct support professional (DSP) trainings, which were in process upon year end. The training was organized under the direction of NC START East's Associate Clinical Director and is designed to enhance provider knowledge of the mental health aspects of IDD, including the application of trauma-informed and bio-psycho-social frameworks.

The program served 194 individuals with IDD-MH throughout the year using a hybrid of telehealth and in-person (when possible) approaches. The NC START East leadership team has been working to normalize, encourage, and praise self-care initiatives for all individuals. Clinical supervision has included focused segments on self-care and wellness, the biopsychosocial approach, and cultural competency. The team utilized the revised START intake as a venue to discuss biopsychosocial vulnerabilities for all new cases. Program staff are actively using the cultural competency section in the intake to have open and constructive dialogue with families, individuals, and other systems partners.

The NC START East team revitalized the Advisory Council this year and members provide excellent system awareness, open discussion, and a high level of interest in the START model. The group is focused on highlighting how START can be valuable to each agency and provider role and what can be done to improve supports and partnerships.

The team worked closely with community partners throughout the pandemic to ensure that individuals enrolled in START and their caregivers had access to telehealth support. For individuals unable to attend planned sessions in person or via telehealth, NC START East offered supplies, materials and activity information for caregivers and families to use with the person enrolled in START.

NC START West

The NC START West served 266 persons with IDD-MH during the reporting period. The program has the highest rate of stable in-activations and the lowest rates of disengagement from services prior to stability in NC START this reporting period. While there was some coordinator turnover during the year, leadership remains strong, and the program continues to meet or exceed all expectations for certified programs. Some staff left the program for reasons related to professional growth, but also took the START philosophy with them. This helps to build capacity across community mental health and IDD service systems and creates new partnerships and referral sources for START.

NC START West completed 12 CETs during the year with high attendance and has more than doubled the number of individuals receiving a Comprehensive Service Evaluations. The team also continued to offer education and community training throughout the year and provided over 340 to their community partners.

The program maintained fidelity to the START model and continued to provide the full array of START supports to families during the pandemic using telehealth methods. The NC West team had a low frequency of police involvement during crisis contacts and was able to decrease the frequency of emergency department use post START enrollment by half.

The NC START West resource center functioned at limited capacity throughout the COVID-19 pandemic and the team offered a COVID-19 support group throughout most of the fiscal year. The purpose of this group was to offer a social outlet for adult enrollees who typically attend the resource center for planned stays. In addition to these efforts, resource center staff and START coordinators worked together to deliver and mail therapeutic tools and resources to enrollees. Resource Center staff also sent cards and made outreach phone calls to stay connected with past guests.

The remainder of this report will highlight demographic, service and outcome trends for individuals enrolled in NC START services as well as efforts made by each program to engage, train, and link with community partners.

Section III. NC START Enrollment Trends and Demographics

NC START Enrollment

NC START operates throughout the state of North Carolina as three programs (Central, East and West). The programs began serving adults (18 and older) in 2009 and expanded to children (6-17) in 2016. These three lifespan programs offer the full array of START services including clinical team, resource center, and START therapeutic coaching. While the programs have been operational since 2009, data collection in the START Information Reporting System (SIRS) did not become fully established at NC START until more than halfway through FY14. Therefore, information in this section reflects those individuals whose records are documented in SIRS (n=1603). Data in this report will be separated into three age categories: children (5-17), transition age youth (18-21), and adults (22 and up).

Figure III.A: Percent of Total NC START Population by Region (n=1603)

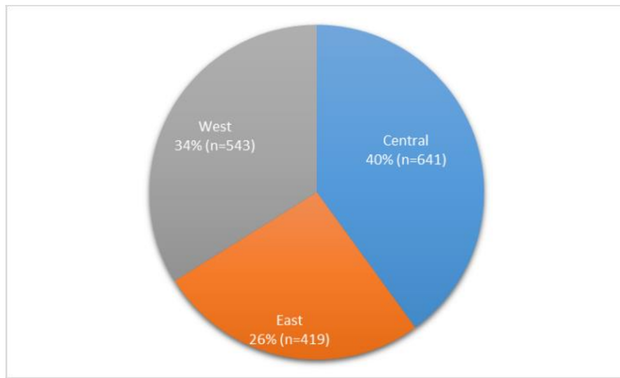


Figure III.B: Percent of FY21 NC START Population by Region (n=734)

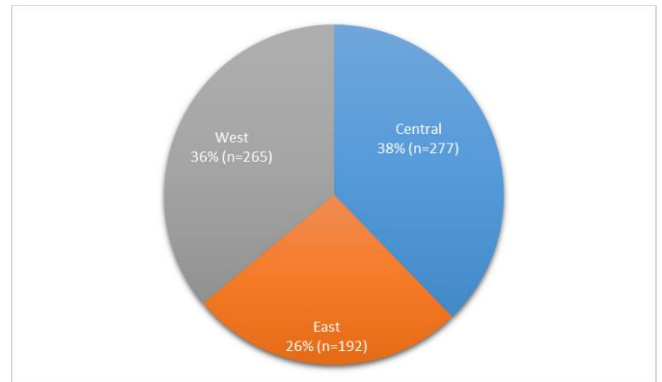


Figure III.C: Percent of FY21 NC START Population by Age Category

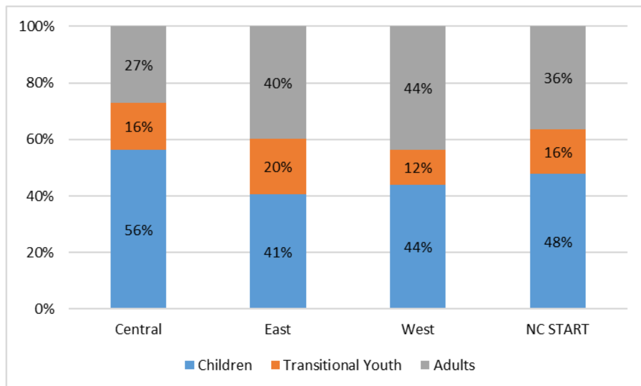
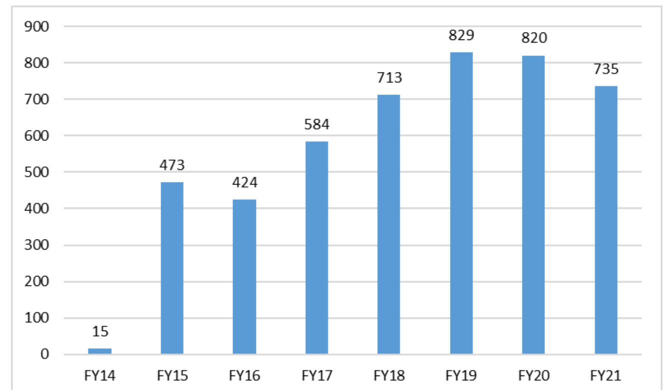


Figure III.D: Total Number* of Individuals Served by NC START by FY



*most individuals are served in multiple fiscal years

Table III.A: NC START Census Summary FY21 (July 1, 2020-June 30, 2021)

***Variable* (n=734)**	**Children**	**Transitional Youth**	**Adults**
Total Served during reporting period N (%)	**282 (38%)**	**119 (16%)**	**333 (45%)**
FY21 New enrollments	90	16	44
Reactivations	9	8	19
Individuals inactivated	**111**	**52**	**151**
Stable functioning	64	41	115
Moved out of START region	3		
No longer requesting services	12	3	8
Long-term hospitalization/residential treatment center	3	1	5
Incarceration			1
Inappropriate for services	2		1
No contact	27	7	17
Deceased			4
Active Caseload at the end of reporting period	171	67	182
Average Caseload size	18		

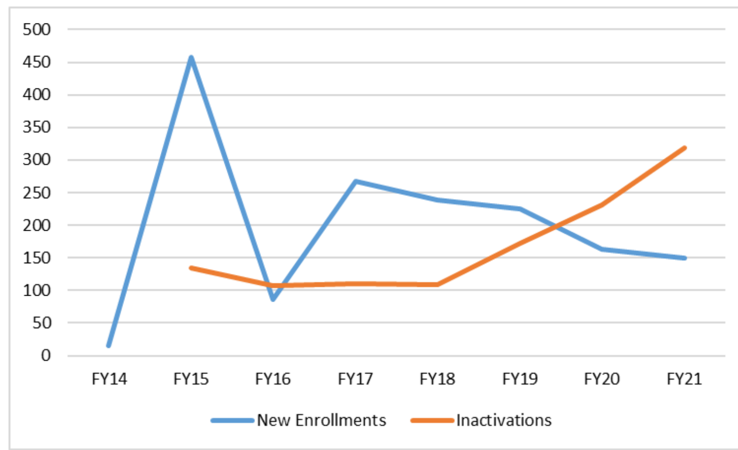
Table III.B: NC START Census Summary by Region, FY21

Variable	**Central**	**East**	**West**
Total Served during reporting period (n=739)*	**279**	**194**	**266**
FY21 New enrollments	53	41	56
Reactivations	16	10	10
Individuals inactivated	**123**	**75**	**121**
Stable functioning	75	51	94
Region transfer	2	2	1
Moved out of START region	1		2
No longer requesting services	11	8	4
Long term hospitalization/residential center	4		5
Incarceration	0	1	
Inappropriate for services	1	1	1
No contact	29	11	11
Deceased		1	3
Active Caseload at the end of reporting period	**156**	**119**	**145**
Average Caseload size	**16****	**21**	**15****

**five individuals were served in multiple regions*

***Central and West experienced significant staff turnover during the reporting period and enacted a referral freeze upon approval from DHHS. It is expected that now that the programs are fully staffed, average caseload size will increase.*

Figure III.E: New Enrollments and In-activations by FY



Summary

The overall NC START census declined in FY21 with fewer new enrollments and a higher rate of inactivations. The increased rate of inactivations was due in part to a joint effort of the NC START programs and DHHS where all cases active for 24 months are now reviewed on a regular basis. Staffing occurs, recommendations are shared, and plans are made to stabilize the circumstances that have resulted in a longer than average stay in START.

Enrollments decreased this reporting period, but it is projected that this will increase in the coming quarters as program staffing stabilizes. Both the Central and West programs experienced significant turnover, which resulted in temporary referral freezes. START leadership were supporting clinical staff to maintain active cases during this transition but were not taking new enrollments. This has since been rectified and staffing has stabilized in both programs.

While most in-activations (69%) were for stability, approximately a quarter (23%) were for disengagement (no longer requesting services, loss of contact). This issue was particularly prevalent in the Central region, where disengagement from services made up 33% of in-activations. The program has surveyed families and providers, have identified contributing factors and are in the process of reviewing their intake protocols to address this issue.

Table III.C: Source of Referral to NC START FY21

Variable	Central	East	West	NC START
N	53	41	56	150
Case Manager/Service Coordinator	94%	88%	96%	93%
Family member/guardian		7%	4%	3%
Community Provider		5%		1%
Hospital/ED	2%			1%
State IDD Center	2%			1%
Unreported	2%			1%

Table III.D: FY21 Presenting Problems at Referral to NC START: Children

Variable	Central	East	West	NC START
N	36	22	32	90
Most Common Reasons for Enrollment				
Aggression	83%	91%	94%	89%
Risk of Placement Loss	22%	23%	3%	16%
Decreased Daily Functioning	17%	23%	6%	14%
DX and Treatment Planning	28%	36%	25%	29%
Family Needs Assistance	78%	64%	69%	71%
Leaving Unexpectedly	39%	27%	44%	38%
Mental Health Symptoms	58%	45%	59%	56%
Self-Injurious Behavior	33%	36%	38%	36%
Sexualized Behavior	19%	9%	19%	17%
Suicidal Action	3%	0%	6%	3%
Suicidal Ideation	17%	18%	28%	21%
Transition from Hospital	19%	5%	9%	12%

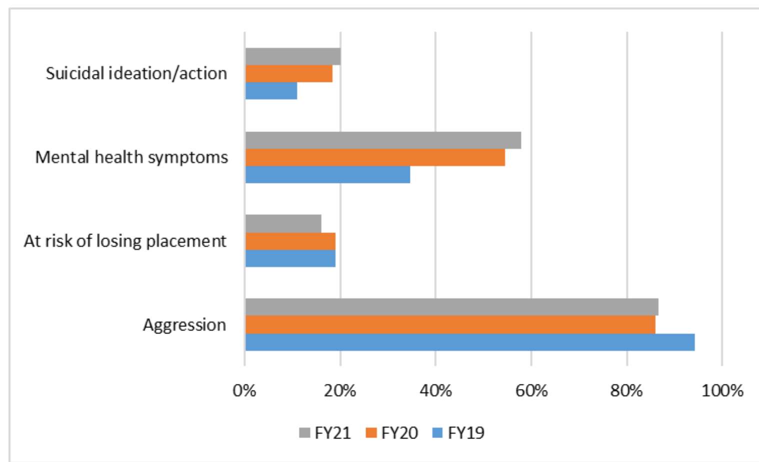
Table III.E: FY21 Presenting Problems at Referral to NC START: Transitional Youth

Variable	Central	East	West	NC START
N	5	6	5	16
Most Common Reasons for Enrollment				
Aggression	40%	100%	80%	75%
Risk of Placement Loss	20%	33%	40%	31%
Decreased Daily Functioning	40%	0%	20%	19%
DX and Treatment Planning	40%	33%	40%	38%
Family Needs Assistance	40%	83%	60%	63%
Leaving Unexpectedly	40%	67%	20%	44%
Mental Health Symptoms	40%	83%	80%	69%
Self-Injurious Behavior	60%	50%	40%	50%
Sexualized Behavior	20%	17%	20%	19%
Suicidal Action	20%	0%	0%	6%
Suicidal Ideation	20%	50%	0%	25%
Transition from Hospital	0%	0%	40%	13%

Table III.F: FY21 Presenting Problems at Referral to NC START: Adults

Variable	Central	East	West	NC START
N	12	13	19	44
Most Common Reasons for Enrollment				
Aggression	67%	100%	89%	86%
Risk of Placement Loss	17%	15%	5%	11%
Decreased Daily Functioning	33%	8%	0%	11%
DX and Treatment Planning	17%	38%	16%	23%
Family Needs Assistance	25%	54%	26%	34%
Leaving Unexpectedly	25%	15%	11%	16%
Mental Health Symptoms	42%	69%	63%	59%
Self-Injurious Behavior	25%	38%	26%	30%
Sexualized Behavior	33%	15%	5%	16%
Suicidal Action	0%	0%	0%	0%
Suicidal Ideation	0%	15%	5%	7%
Transition from Hospital	25%	8%	16%	16%

Figure III.F: Presenting Problems at Referral Trends



Summary

Consistent with other START programs, most individuals are referred by Care Managers/Service Coordinators. Previous research has shown that families in greatest need often do not engage the system of care until there are serious, emergent situations, and even then, not consistently. This highlights the importance of START linkages so that families who may benefit from START are engaged and that other supports, such as schools and mental health providers, understand the referral process. While aggression remains the most common reason for referral, both mental health symptoms (65%) and suicidal ideation/action (81%) have increased markedly since FY19. This change is consistent with research suggesting that overall mental health symptoms have

increased during the COVID-19 pandemic compared to similar time periods pre-pandemic.[4] Other reasons for referral such as self-injurious behavior, leaving unexpectedly, sexualized behavior, family needs assistance, and hospital transition have remained quite consistent since FY19. In FY21, about 16% of individuals referred to NC START were reportedly at risk for placement loss at referral. Of those, 30% experienced a placement change during the year, compared with under 15% of the NC START population overall in FY21. This is a trend that warrants additional review in the coming year to further explore predictors of residential instability of START service users in North Carolina.

Demographics

This section provides demographic and diagnostic trend data for all persons served by NC START (n=739) during FY21.

Table III.G Age, gender, race, level of ID, and living situation of START service users

Variable	Central	East	West	NC START
N	279	194	266	739
Mean Age (min-max)	20 (6-58)	23 (7-61)	24 (6-69)	23 (6-69)
Gender (% male)	70%	74%	64%	69%
Race				
White/Caucasian	44%	59%	68%	57%
African American	43%	35%	24%	34%
Asian	2%	0%	1%	1%
American Indian or Alaska Native	0%	1%	1%	1%
Multi-Racial	6%	3%	5%	5%
Other	0%	1%	0%	0%
Unknown	4%	2%	2%	3%
Ethnicity (% Hispanic)	9%	3%	3%	5%
Level of Intellectual Disability (%)				
No ID/Borderline	16%	11%	10%	13%
Mild	46%	38%	45%	44%
Moderate	21%	35%	30%	28%
Severe/Profound	6%	11%	11%	9%
None Noted	10%	5%	4%	7%
Living Situation (%)				
Family	59%	57%	52%	56%
Foster Care	1%	3%	3%	2%
Alternative Family Living (AFL)	6%	8%	15%	10%
Group Home, Community ICF/DD	19%	21%	14%	18%
Independent/Supervised	1%	3%	2%	2%
Psych. Hospital/IDD Center/PRTF	10%	7%	9%	9%
Other (Nursing home, Homeless)	4%	1%	4%	3%

[4] Czeisler MÉ , Lane RI, Petrosky E, et al. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. MMWR Morb Mortal Wkly Rep 2020; 69:1049–1057. DOI: http://dx.doi.org/10.15585/mmwr.mm6932a1external icon

Summary

Many NC START demographic factors are consistent with national START trends. NC START programs serve culturally diverse communities. To ensure access to care, START teams continue to work to hire staff who can accommodate the cultural and linguistic needs of those served. NC START currently has five bi/multi-lingual staff (Spanish, German and American Sign Language) and START tools and assessments are available in Spanish. Such diversity within NC START fosters a foundation of understanding cultural norms and differences and ensures that therapeutic services are provided through a lens of cultural and linguistic competency.

At enrollment, 12% of the FY21 NC START population were living in facility-based settings (hospitals, IDD Centers, psychiatric residential treatment centers or nursing homes) or were homeless. Of those, only a quarter are now reported to be living in community settings. Individuals still living in facility-based settings should be reviewed to determine if additional work may need to be done to assist individuals in moving to less restrictive community settings.

Mental Health and Chronic Health Conditions

Table III.H: Percent of NC START enrollees with mental health conditions reported at intake: Children

Variable	Central	East	West	NC START
N	126	67	91	284
Mental Health Conditions (%)				
At least 1 diagnosis	90%	96%	98%	94%
Mean Diagnoses (range)	2.7 (1-6)	2.5 (1-5)	2.6 (1-6)	2.6 (1-6)
Frequency of Common MH Conditions (%)				
Anxiety Disorders	16%	6%	19%	14%
ADHD	65%	69%	68%	67%
ASD	67%	72%	65%	68%
Bipolar Disorders	6%	9%	4%	6%
Depressive Disorders	19%	27%	23%	22%
Disruptive Disorders	37%	31%	43%	38%
OCD	3%	0%	2%	2%
Personality Disorders	0%	0%	0%	0%
Schizophrenia Spectrum Disorders	2%	0%	4%	2%
Trauma/Stressor Disorders	20%	12%	21%	18%

Table III.I: Percent of NC START enrollees with mental health conditions reported at intake: Transitional youth

Variable	Central	East	West	NC START
N	46	33	41	120
Mental Health Conditions (%)				
At least 1 diagnosis	91%	100%	100%	98%
Mean Diagnoses (range)	2.4 (1-5)	2.5 (1-5)	2.9 (1-6)	2.6 (1-6)
Frequency of Common MH Conditions (%)				
Anxiety Disorders	13%	6%	22%	14%
ADHD	50%	36%	49%	46%
ASD	65%	52%	61%	60%
Bipolar Disorders	11%	21%	10%	13%
Depressive Disorders	35%	39%	37%	37%
Disruptive Disorders	22%	42%	51%	38%
OCD	0%	12%	5%	5%
Personality Disorders	0%	3%	0%	1%
Schizophrenia Spectrum Disorders	4%	9%	7%	7%
Trauma/Stressor Disorders	15%	30%	29%	24%

Table III.J: Percent of NC START enrollees with mental health conditions reported at intake: Adults

Variable	Central	East	West	NC START
N	107	94	134	335
Mental Health Conditions (%)				
At least 1 diagnosis	89%	96%	96%	94%
Mean Diagnoses (range)	2.1 (1-5)	1.9 (1-5)	2.2 (1-7)	2.1 (1-7)
Frequency of Common MH Conditions (%)				
Anxiety Disorders	10%	9%	20%	14%
ADHD	26%	19%	23%	23%
ASD	31%	35%	28%	31%
Bipolar Disorders	21%	14%	19%	18%
Depressive Disorders	18%	24%	26%	23%
Disruptive Disorders	25%	20%	29%	25%
OCD	4%	4%	7%	5%
Personality Disorders	2%	6%	9%	6%
Schizophrenia Spectrum Disorders	24%	32%	22%	26%
Trauma/Stressor Disorders	13%	12%	19%	15%

Figure III.G: Most frequent mental health condition by FY: FY18-FY21: All NC START

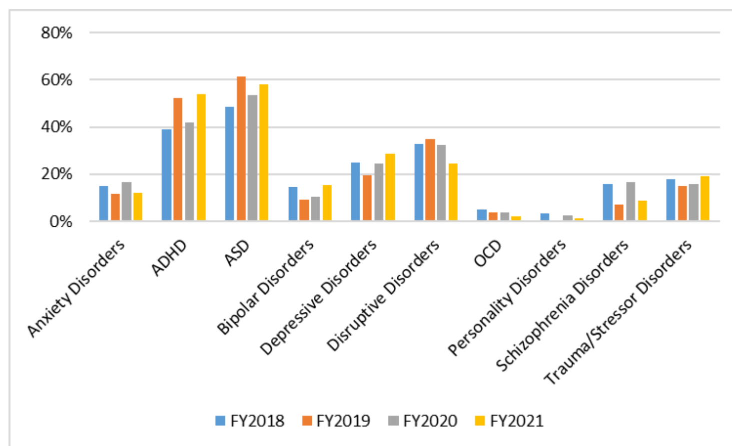


Table III.K: Percent of NC START enrollees with chronic medical conditions reported at intake: Children

Variable	Central	East	West	NC START
N	126	67	91	284
Medical Diagnosis (%)				
At least 1 diagnosis	52%	52%	51%	51%
Mean Diagnoses	1.6 (1-7)	1.7 (1-5)	1.8 (1-5)	1.7 (1-7)
Frequency of Most Common Med. Cond. (%)				
Cardiovascular	2%	1%	1%	1%
Endocrine	4%	4%	5%	5%
Gastro/Intestinal	7%	7%	13%	9%
Immunology/Allergy	6%	3%	12%	7%
Musculoskeletal disorders	1%	3%	3%	2%
Neurologic	19%	15%	13%	16%
Obesity	2%	1%	2%	2%
Pulmonary disorders	8%	13%	8%	9%
Sleep Disorder	2%	0%	4%	2%

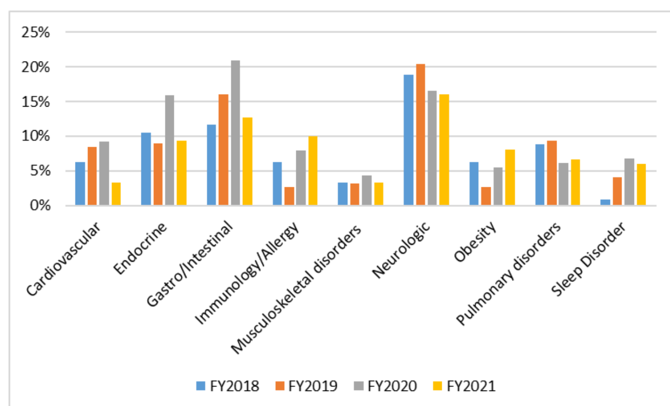
Table III.L: Percent of NC START enrollees with chronic medical conditions reported at intake: Transitional Youth

Variable	Central	East	West	NC START
N	46	33	41	120
Medical Diagnosis (%)				
At least 1 diagnosis	52%	67%	68%	66%
Mean Diagnoses	1.7 (1-5)	1.7 (1-6)	1.9 (1-6)	1.8 (1-6)
Frequency of Most Common Med. Cond. (%)				
Cardiovascular	2%	12%	0%	4%
Endocrine	9%	12%	20%	13%
Gastro/Intestinal	17%	18%	29%	22%
Immunology/Allergy	2%	12%	12%	8%
Musculoskeletal disorders	2%	0%	12%	5%
Neurologic	13%	18%	7%	13%
Obesity	7%	0%	7%	5%
Pulmonary disorders	4%	6%	2%	4%
Sleep Disorder	2%	6%	2%	3%

Table III.M: Percent of NC START enrollees with chronic medical conditions reported at intake: Adults

Variable	Central	East	West	NC START
N	107	94	134	335
Medical Diagnosis (%)				
At least 1 diagnosis	55%	68%	75%	67%
Mean Diagnoses	2.3 (1-6)	2.5 (1-12)	2.2 (1-6)	2.3 (1-12)
Frequency of Most Common Med. Cond. (%)				
Cardiovascular	12%	26%	11%	16%
Endocrine	17%	19%	17%	18%
Gastro/Intestinal	12%	23%	23%	20%
Immunology/Allergy	9%	6%	7%	8%
Musculoskeletal disorders	7%	4%	8%	7%
Neurologic	12%	23%	26%	21%
Obesity	10%	10%	13%	11%
Pulmonary disorders	5%	11%	6%	7%
Sleep Disorder	5%	6%	10%	7%

Figure III.H: Most frequent chronic medical condition by FY: FY18-FY21: All NC START



Summary

The frequency of trauma/stressor related disorders in both children and transitional youth is higher than other START numbers nationally (9% for children and 12% for transitional youth/adults). This suggests education and acknowledgement of the impact of trauma and other stressor related disorders across the system. These findings support the need to continue to support community education around trauma informed care.

More than half of children and 2/3 of transitional youth/adults report medical comorbidities, with neurological, endocrine, and GI issues being most prevalent. The continued work of NC START on identifying medical issues is a critical role of START teams, since, when not identified and treated, persons with IDD may experience challenges that are identified as related to the person's mental health when there may be other root causes for distress.

NC START embraces a wellness model that extends beyond just biological health and incorporates emotional, social, and spiritual fulfillment as a proactive strategy for improving overall health of enrolled individuals. This model extends to staff with programs working to infuse a culture of wellness and self-care within the teams. This has been especially important during the COVID-19 pandemic. Therefore, team meetings often include a time to work on personal coping techniques and emotional status so that fundamentals of PERMA and well-being are being modeled both within NC START and applied to the people and community systems supported by NC START.

Section IV. NC START Program Outcomes

Primary outcomes of the START model are decreases in emergency service use and challenging mental health presentations, which secondarily improve quality of life and PERMA for enrollees, their families, and the system of support. START cross systems crisis prevention and intervention planning along with 24-hour crisis response are designed to directly affect these outcomes.

Emergency Service Trends

A number of NC START service recipients have a history of emergency service use prior to enrollment in START services. Figure IV.A looks at emergency service trends for individuals one year prior to enrollment in START and emergency service utilization for individuals post START enrollment. A target goal of the START program is to help avoid unnecessary emergency service use and reduce recidivism. Reported post enrollment rates reflect indiviudals enrolled for a variety of different time periods and, because many indiviudals in NC START have had more than one period of active enrollment in START, only emergency services associated with the most recent enrollment are included. Results reflect consistent overall trends in the reduction of emergency service use post enrollment in NC START services. The reduction in emergency service use suggests that the START commitment to principles of positive psychology and wellness in addition to maintaining fidelity to START service elements such as comprehensive assessment and evaluation, cross-systems crisis planning, outreach, and emergency response can be effective in improving the outcomes for individuals enrolled in services.

In addition to planned START clinical services, all NC START teams provide 24-hour crisis support to enrolled individuals and their families/caregivers. NC START responded to over 400 crisis calls in FY21. Since nearly all crisis contacts occurred during COVID-19 restrictions, the majority (90%) were conducted using telehealth technology. About 60% of those contacts resulted in individuals remaining in their current setting (52%) or being treated and released from the emergency department (7%). While only a small number (5%) had a psychiatric admission following a crisis contact, NC START continues to have a high number of calls involving police intervention (43%) and 27% of individuals utilizing NC START crisis response were held in the emergency department for over 24 hours.

Table IV.A: Change in frequency of pre- and post-START emergency service utilization by region

Variable	Central	East	West	NC START
N	279	194	266	739
Psychiatric Admissions				
Prior to enrollment	127 (46%)	92 (47%)	123 (46%)	342 (46%)
Mean (min-max)	1.9 (1-10)	1.8 (1-8)	2.0 (1-15)	1.9 (1-15)
During enrollment	59 (21%)	51 (26%)	65 (24%)	175 (24%)
Mean (min-max)	1.5 (1-4)	2.6 (1-13)	2.2 (1-12)	2.1 (1-13)
Length of Stay	41 days	23 days	27 days	29 days
Emergency Dept. Visits				
Prior to enrollment	151 (54%)	118 (61%)	155 (58%)	424 (57%)
Mean (min-max)	3.1 (1-15)	2.7 (1-19)	4.2 (1-100)	3.4 (1-100)
During enrollment	121 (43%)	89 (46%)	76 (29%)	286 (39%)
Mean (min-max)	3.3 (1-20)	3.8 (1-22)	2.5 (1-12)	3.3 (1-22)

Table IV.B: NC START crisis response FY21 by region

Variable	Central	East	West	NC START
Crisis Contacts				
Number of Individuals with a contact	77	37	30	144
Number of Crisis Contacts	223	114	82	419
Number with 10 or more calls	0	2	2	4
Percent done via telehealth (video or phone)	87%	92%	94%	90%
Law Enforcement Involvement	54%	41%	13%	43%
Crisis Disposition for each crisis contact N (%)				
Maintain Setting	52%	73%	82%	63%
Psychiatric Hospital Admission	5%	6%	2%	5%
Emergency Department (released)	7%	4%	1%	5%
Emergency Department (held over 24 hrs.)	27%	6%	10%	18%
Emergency Department (unspecified)	4%	3%	1%	3%
Medical Hospital Admission	3%	4%	0%	3%
Non-START crisis stabilization	2%	4%	4%	3%

Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item informant reported psychopathology rating tool designed specifically for use with individuals with IDD (Aman, Burrow, & Wolford, 1997). It is administered to enrollees at intake and 6-month intervals. The ABC has been reported in literature as an *outcome measure*, demonstrating sensitivity to changes in psychopathology ratings over time. The ABC is used by START teams to determine if services provided are associated with reduced psychopathology ratings over 6-month periods. The authors suggest the use of ABC subscales, not a total scale score. Through factor analysis, three of these subscales have been found to be sensitive to START treatment effects: *Irritability*, *Hyperactivity* and *Lethargy*. These subscales are reported below for NC START enrollees.

For this analysis, individuals enrolled in START for at least 6 months with at least two ABCs were included. Table IV.C shows the percentage of individuals in NC START who had a decrease in scores (improvement in symptoms) between initial assessment at intake and the most recent ABC assessment completed (avg. of 29 months later). A t-test analysis was done for all regions for both adults and children. In all cases the decrease in mean scores between initial and most recent ABC were statistically significant. The national average scores on the ABC for children are higher than adults but there is very little difference between children and adults in the percentage showing improvement between the initial and most recent ABC assessment. The results of the aggregate t-test for children, transitional youth, and adults are provided in Tables IV.D, IV.E and IV.F.

Table IV.C: Percentage of individuals with improvement between first and most recent ABC by subscale

ABC Subscale	Central (n=227)	East (n=163)	West (n=235)	NC START (n=625)
Hyperactivity/Noncompliance	69%	72%	65%	68%
Irritability/Agitation	66%	66%	67%	66%
Lethargy/Social Withdrawal	60%	67%	56%	60%

Table IV.D: ABC Analysis: NC START Children

		Mean Score			
Children (n=223) Average elapsed time: 21 months	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one- tail**
Hyperactivity/Noncompliance	71%	26.71	19.83	8.63	0.00
Irritability/Agitation	62%	23.85	18.14	7.53	0.00
Lethargy/Social Withdrawal	59%	12.43	9.45	4.74	0.00

Alpha=0.05

Table IV.E: ABC Analysis: NC START Transitional Youth

		Mean Score			
Transitional Youth (n=109) Average elapsed time: 28 months	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one-tail**
Hyperactivity/Noncompliance	73%	25.23	16.97	6.94	0.00
Irritability/Agitation	71%	23.52	16.17	6.32	0.00
Lethargy/Social Withdrawal	64%	13.50	8.81	5.22	0.00

Alpha=0.05

Table IV.F: ABC Analysis: NC START Adults

		Mean Score			
Children (n=293) Average elapsed time: 37 months	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one- tail**
Hyperactivity/Noncompliance	65%	18.19	13.60	6.50	0.00
Irritability/Agitation	68%	19.51	14.75	6.99	0.00
Lethargy/Social Withdrawal	59%	11.30	8.58	4.86	0.00

Alpha=0.05

Figure IV.A: Change in frequency of pre- and post-START enrollment emergency service utilization: All NC START

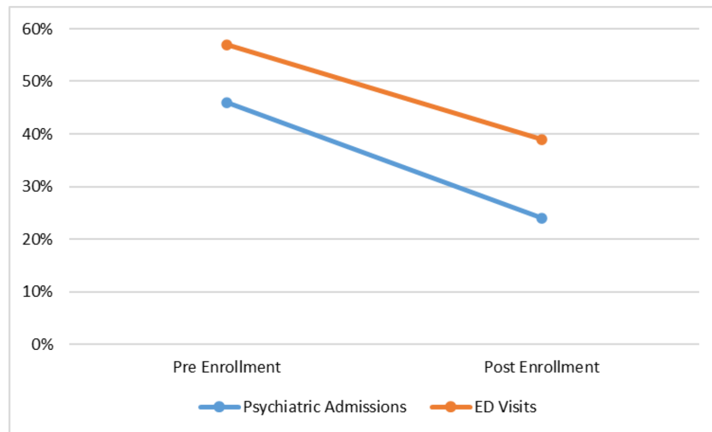


Figure IV.B: Disposition of START crisis contacts: All NC START

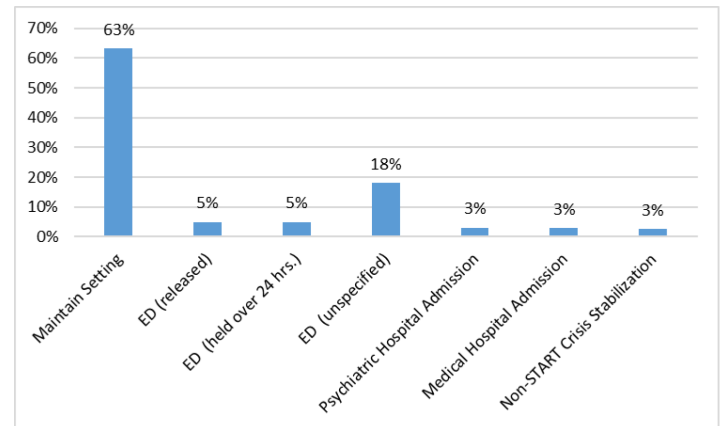
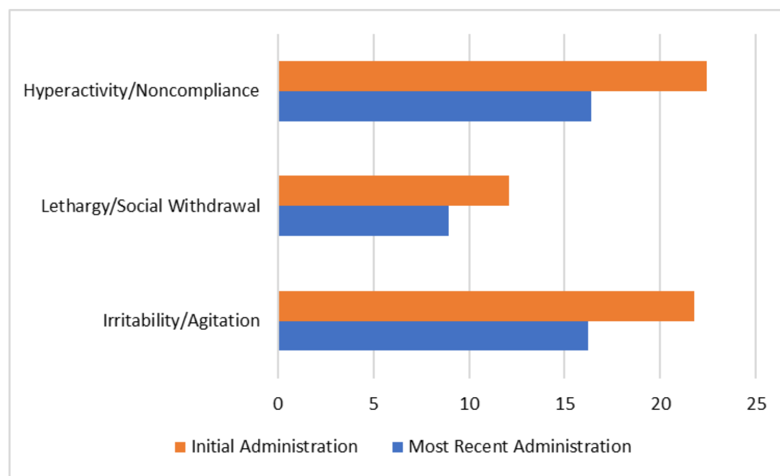


Figure IV.C: Change in mean ABC scores between first and most recent administrations: All NC START



Summary

Research of ABC scores for individuals receiving START services indicates that the lethargy and irritability subscales are strong predictors of emergency service use[5]. NC START data for the three main subscales used to assess intervention effectiveness show a significant decrease in the psychopathology ratings following initiation of START services. This is consistent with results in previous years and is another indication that NC START continued to work effectively with START enrollees during COVID.

NC START teams consistently demonstrate success in the three outcome measures shown in this section (decreased emergency service utilization, maintaining environment following a crisis and decreased ABC scores). Teams will continue to work with individuals not just in decreasing crisis events, but also in improving PERMA and well-being. Next year's report will include data on coordinator spotted strengths of enrolled individuals, residential stability following enrollment in NC START, and caregiver stress as measured by the START plan.

[5] Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalization among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research*, *60*(12), 1153-1164.

Section V. Planned START Services

This section provides a descriptive analysis of NC START planned services for FY21, including Clinical Education Team Meetings (CETs) held, community outreach and training, and clinical services.

NC START Clinical Education Teams and Community Trainings

All NC START programs continued to conduct virtual CETs and community trainings throughout the fiscal year. NC START CETs are very well attended and reached more than 1000 professionals statewide. The attendance rates ranged from 13 to 86 participants and the average attendance was 33. Table V.A provides a list of CET topics offered over the last year.

Table V. A: NC START Community Education Team Meetings (CETs)

Region	Training Topic
Central	Reactive Attachment Disorder
	Prevalence of ADHD and IDD
	Building Resilience through Supportive Strategies
	Fetal Alcohol Spectrum Disorder
	Diagnostic Overshadowing of Medical Concerns (focus on diabetes)
	Complicated and Traumatic Grief
	Suicidal Ideation and Adapted Support Strategies
	Borderline Personality Disorder, Trauma and IDD
	Anxiety and Adapted DBT Approaches (two dates)
	Executive Functioning Deficits and Strength Based Approaches
East	Sexual Health and individuals with IDD
	Anxiety and Autism: Treatment Implications
	Aces in individuals with ID/DD
	Under pressure: Caregiver Strain and Compassion Fatigue
	To Change or not to Change: Reaching Beyond Stability in the ID/DD Population
	Unraveling Complex Presentations: Where to START
	Crisis Prevention, Intervention, and Response for IDD/MH
	Behavioral Health Implications of Seizures in Individuals with Intellectual Disabilities
	Autism and ADHD

West	Pancytopenia & PERMA
	Special Interests in Individuals with ASD
	Symptoms of Psychosis in Individuals with IDD
	Differential Diagnosis – IDD & Comorbid MH
	Childhood Onset Schizophrenia
	Sensory Integration Dysfunction
	Rethinking Disruptive Behavior Disorders
	ADHD
	Borderline Personality Disorder
	RAD or ASD
	Recognizing Suicidality in Persons with IDD
	FASD

In addition to CETs, NC START provides regular training to a variety of partners including emergency services, residential and day providers, mental health providers, and educators. Table V.B provides the total training episodes and training hours offered by the NC START programs. More details about the type of training offered to community partners, as well as linkage agreements can be found in the Appendix B.

Table V. B: NC START Community Training Events and Hours

	Central	East	West	NC START
Total Community Outreach/Training Episodes (N)	112	56	147	315
Total Hours of Community Outreach/Training	240 hours	206 hours	340 hours	786 hours

NC START Clinical Services

START model service interventions aim to ensure that individuals are getting the supports they need and are designed to intervene effectively in times of stress and crisis, avoiding costly and restrictive emergency services. All START programs offer the following planned services. Time spent on these activities is tracked in SIRS.

- *Intake/Assessment:* Work done to determine the needs of the individual, the team, and the services to be provided. This includes: Information/record gathering; intake meetings; completion of assessment tools; and START Action Plan development.
- *Outreach*: Any time a START Coordinator provides education or outreach to the system of support (families/natural supports, residential programs, day programs, schools, mental health facilities), or any entity that may seek or need additional outreach and education.
- *Clinical Consultation*: Consultations provided by the Clinical Director with community team members who support individuals. Recommendations are given and facilitation of goal and action plan development is done by the START Coordinator.
- *Medical Consultation:* Consultation provided by the Medical Director about diagnostic, medical, or polypharmacy issues. Services can include collaboration with the individual's team prior to a psychiatric appointment, accompanying the team to the appointment, medication history review by the START team, and outreach provided by the Medical Director to the treating provider.
- *Cross System Crisis Prevention and Intervention Planning (CSCPIP)*: Collecting and reviewing relevant information; brainstorming with the system of support; developing/writing, distributing, reviewing/revising the CSCPIP; training and implementation.
- *Crisis Follow-Up*: Time spent following up to coordinate services and supports after a crisis.

- *Facilitation of Planned Therapeutic Supports (Resource Center, Therapeutic Coaching)*: Coordination, preparation for, and/or facilitation of planned center admission or therapeutic coaching.
- *Comprehensive Service Evaluation (CSE)*: Receiving and reviewing records; interviewing the individual and system of support; writing the CSE; collaborating with START Clinical and Medical Directors on development of evaluation and recommendations; reviewing recommendations with person's system of support and developing an action plan.

The NC START programs began providing telehealth services in response to COVID-19 and statewide social distancing requirements. Telehealth services began in March 2020 and continued throughout the year. Additional fields in SIRS were added to track telehealth outreach, therapeutic coaching visits, and crisis follow-up. The percent of individuals who received telehealth services is in the table below. Table V.C shows the percent of individuals enrolled in each region who received planned START services during the report period. Since individuals are enrolled at different points in time and have unique strengths and needs, not all enrollees received each planned service in the reporting period. However, there are certain expected benchmarks that all START programs should be meeting in order to assure fidelity.

Table V.C: Provision of Planned START Clinical Services: In-person and Telehealth

Variable	Central	East	West	NC START
N	279	194	266	739
Planned Services (% of Individuals)				
Outreach	89%	95%	98%	94%
Intake/Assessment	78%	90%	91%	86%
CSCPIP	58%	73%	65%	64%
Clinical Consultation	63%	75%	86%	75%
Medical Consultation	24%	13%	51%	31%
Therapeutic Supports	34%	39%	28%	33%
Crisis Follow-Up	32%	25%	24%	27%
Any Telehealth Service	86%	96%	95%	92%

START Tools and Assessments

START clinical services include the use of standard tools and assessments and are included below in Table V.D. They are re-administered or updated on a regular basis as long as the individual is enrolled and actively receiving START Services.

Table V.D: Percentage of active individuals who received assessments/tools: Completed (up to date at conclusion of FY)

START Tools	Central	East	West	NC START
START Action Plan	97% (79%)	100% (97%)	98% (80%)	99% (85%)
Aberrant Behavior Checklist (ABC)	97% (80%)	99% (96%)	99% (88%)	99% (87%)
Recent Stressors Questionnaire (RSQ)	97%	97%	99%	98%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	94% (85%)	94% (94%)	99% (91%)	96% (90%)
Comprehensive Service Evaluation (CSE)	4%	5%	13%	8%

Summary

Community outreach is a strength of NC START. Despite COVID-19 restrictions, they continued to provide regular community training and education- much of it delivered virtually. CET attendance for all NC START programs is very high (average 33) and the programs provide education and training on a wide range of topics. NC START programs use Qualtrics to evaluate their CETS and over 98% of participants report being highly satisfied (65%) or satisfied (33%) with their experience and over 90% plan to share what they have learned with others in their community.

More than 94% of persons enrolled in START received outreach during the course of the reporting period and 92% of the START population received some telehealth services as well. With the exception of CSEs, START plans and tools were completed within expectations for certified programs. While CSE completion has nearly doubled from last year, it still falls below the expected 15-20%, and all programs will need to develop a training plan to improve CSE completion rates in the coming year.

Section VI. START Therapeutic Supports

START therapeutic supports include coaching and resource center services. This section provides overviews and descriptive analyses of these NC START services.

START Therapeutic Coaching

START Therapeutic Coaching (STC) is part of the START crisis prevention and intervention continuum and is designed to assess and stabilize a person in their community environment(s). STC provides planned and emergency strengths-based, clinical coaching to primary caregivers and persons in their home setting to help them reframe presenting challenges. The START Coordinator works directly with the person and their caregivers to determine the need for and interest in STC. Following this a referral is made. In most cases, STC is planned in coordination with coaches that are familiar with the person and the setting. However, in some situations the service may be provided in a more urgent capacity. STC visits may also be utilized to enhance overall wellness of the person by gaining a better understanding of biopsychosocial risk and protective factors. The provision of coaching supports may occur in any environment, any day of the week, and will depend on the cross-systems crisis prevention and intervention plan (CSCPIP) and need for services that are outlined in the plan.

Due to COVID-19 pandemic restrictions, the NC START provided both in-person and telehealth coaching sessions to over 25% of individuals enrolled in NC START.

Table VI.A: NC START Therapeutic Coaching Activity

Central	**Therapeutic Coaching/Group**		
	Children	Transitional Youth	Adults
Planned: # of Individuals (total hours)	18 (477)	6 (85)	11 (162)
Telehealth: # of Individuals (total hours)	19 (158)	9 (78)	25 (327)
Emergency: # of Individuals (total hours)	5 (12)	1 (2)	1 (3)
Telehealth Support Group: # of Individuals (total hours)			16 (118)
East	**Children**	**Transitional Youth**	**Adults**
Planned: # of Individuals (total hours)	3 (19)		5 (54 hours)
Telehealth: # of Individuals (total hours)	6 (26 hours)	1 (4 Hours)	11 (81 hours)
Emergency: # of Individuals (total hours)			
Telehealth Support Group: # of Individuals (total hours)			
West	**Children**	**Transitional Youth**	**Adults**
Planned: # of Individuals (total hours)	3 (37)		7 (65)
Telehealth: # of Individuals (total hours)	10 (102 hours)	4 (74 Hours)	13 (230 hours)
Emergency: # of Individuals (total hours)			2 (145)
Telehealth Support Group: # of Individuals (total hours)			7 (21 hours)

START Resource Center Services

The following tables reflect utilization of the NC START Resource Centers. The programs have four beds, half of which are designated for planned admissions. Planned admissions are intended to serve adults who live with their families or natural supports and have not been able to use respite in more traditional settings. Depending on the needs of the person and their family, the frequency and length of planned admissions may vary but typically average about 5 days per admission. The other two beds are designated for emergency admissions, which serve adult enrollees experiencing acute crises. Emergency admissions are longer and typically average about 17 days, during which time, guests received assessment and individualized intervention and discharge planning.

In FY21, planned admissions were largely halted due to COVID-19 restrictions, but the NC START Resource Centers continued to serve individuals on an emergency basis as conditions allowed. The programs operated at a 2-bed capacity for much of the reporting period to comply with social distancing guidelines. Because of the change in circumstances as a result of COVID-19, recidivism and occupancy rates cannot be calculated for the year. Below are the total number of visits per region, the average length of stay and the range of admission days.

Table VI.B: NC START Center-based Therapeutic Supports

Variable	Central	East	West
Number of individuals admitted	14	13	23
Total number of admissions	21	36	41
Range of days	3-30	3-20	1-33
Avg LOS (days)	16	12	14
Mode (days)	28	15	14
Total time spent in resource center (days)	349	448	477

Summary

The START resource centers and therapeutic coaching programs continued to operate throughout the pandemic as restrictions and safety considerations allowed. Therapeutic coaching continues using a combination of telehealth and in-person options. Limited occupancy was a mainstay in all three NC START resource centers this year, with each program doing their best to serve adult enrollees in both emergency and planned capacities. The Central and West programs had staff and guests who were directly impacted by COVID-19, which did result in temporary closing and cleaning. The East remained open throughout the duration of the reporting period. At this time, the programs have resumed planned admissions and aim to have three beds occupied at any given time. This remains a challenge due to staffing and continued hesitancy on the part of families to send their loved ones to the centers. START service users and their families continue to express interest and appreciation of the START centers but have a desire to delay some admissions until COVID-19 cases in NC stabilize. The programs plan to work together to develop a tracking mechanism for these instances in the coming year.

Section VII: Conclusion and Recommendations

The NC START programs continue to meet clinical team fidelity requirements and all operate as fully certified programs. The following are START model recommendations for the NC START programs for fiscal year 2022. These recommendations apply to all NC START programs. The teams will work directly with Center for START Services project managers to develop plans to address these recommendations.

Recommendations

- NC START leadership should develop a plan to maximize new enrollments in the coming fiscal year. They should target active caseloads of 25-30 individuals per full-time START coordinator.
- NC START programs should document all residential transitions in SIRS to help determine if enrollment in START can impact placement loss over time.
- Program leadership should continue to review monthly SIRS reports carefully to ensure that program fidelity is maintained. Team leaders are also encouraged to utilize built-in program reports from SIRS to track progress and address any concerns promptly.
- Closely monitor all occurrences of individuals enrolled in START who are made inactive due to disengagement, in order to inform new approaches to engaging referral sources, families, and individuals who can potentially benefit from START services.
- It is also important to monitor length of stay and assure that services provided are comprehensive, effective, and timely. It is recommended that that all cases that are active for 2 or more years be assessed and staffed with Center for START Services and program staff.
- As more information regarding service users' level of ID is obtained through working with the person's system, SIRS data should be updated. A clear understanding of each person's intellectual and adaptive functioning is critical in developing and providing the best supports.
- Primary outreach and educational efforts should continue on the importance of identifying the bio/psycho/social needs of all individuals supported by NC START. NC START programs should continue to offer training on accurate diagnostic case formulations and the recognition of anxiety, trauma related issues, and medical comorbidities in individuals with IDD to a broader audience of community partners.
- Ensure that all enrollees' START tools are completed, up to date, and entered into SIRS. START tools, especially the CSCPIP, are the cornerstone of START services and lay the foundation for comprehensive, biopsychosocial case conceptualization. This makes it imperative that assessments and tools are updated within required timeframes. Review of these data should demonstrate increased compliance rates at a level of 90% or greater by the end of the next quarter.
- Leadership team and supervisors should develop a plan for each coordinator to complete CSEs on a regular basis and track these data to achieve a completion rate of at least 10%. The teams should prioritize individuals who are experiencing the highest rate of emergency services use or crisis contacts. CSS leadership team members could also assist with this process.
- NC START programs should put education in place to encourage caregivers to utilize the START crisis line prior to calling law enforcement or going to the emergency room whenever clinically appropriate. Improved education around the use of the crisis line may further decrease emergency department utilization and reduce police involvement with enrolled individuals.

Appendix A: Center for START Services Training, Technical Assistance, and Consultation

Center for START Services Training Groups

Many START methods are unique to the model and incorporate best practices, START tools, and strategies to implement them. To develop proficiency, program staff participate in comprehensive training on these methods along with didactic training on the mental health aspects of intellectual and developmental disabilities. Training provided by the Center for START Services is targeted to the NC START programs along with the community as a whole.

START Coordinator Training

START Coordinators and leadership staff complete a training course through CSS's online learning platform, Moodlerooms, with the goal of achieving START Coordinator Certification. Participation in the course requires enrollment in a 19-week Coordinator Training Group facilitated by CSS instructors. A combination of asynchronous training and web-based group dialogue is used. For office hours connected to the course, the participant identifies topics based on areas for their own professional growth. Frequent topics for office hour sessions include crisis planning, emergency response and evaluation, outreach, case conceptualization, and systemic consultation strategies.

Therapeutic Coaching Training

Therapeutic coaches complete an 8-week Therapeutic Coaching Training Group facilitated by CSS. Using the same training methodology as the START Coordinator Certification Curriculum, the START Therapeutic Coaching Course is accessed concurrently along with participation in a training group that serves as an opportunity for the coaches to process and discuss information learned within the course and demonstrate their ability to generalize information learned across settings.

Additional Center for START Services Training and Consultation

In addition to technical assistance and training provided directly to NC START program staff, there are other ongoing training offerings sponsored by the Center for START Services that are available to NC START and their partners.

START National Online Training Series

The START National Online Training Series (NOTS) on Mental Health and IDD is designed to provide innovative and topic-focused training to professionals that serve individuals who experience IDD and mental health needs. Pre-recorded trainings from this series are released once a month to the START Network (on the 3rd Friday of each month) from September through April. The 2020-2021 series also featured a live, virtual 1-hour Q&A session with that month's presenter facilitated by CSS instructors. The series is free for the NC START programs and their partners. A comprehensive Review Guide is also provided for each presentation that can be utilized to independently facilitate small-group discussions between community partners about the material and its application to daily practice. Attendees can receive one contact hour/0.1 UNH CEU for viewing the pre-recorded presentation and completing the online evaluation. Topics offered between 7/1/2020-6/30/2021 were:

- **September 2020:** *START Therapeutic Coaching Strategies for Supporting Individuals with IDD and Suicidal Ideation,* NC START Central: Maggie Robbins, MA, LCAT, RDT, Clinical Director, Meredith Dangel, MA, CRC, Intern & Remy Jodrey, MS, LCMHCA, Therapeutic Coaching Team Leader
- **October 2020:** *Skills System: Strategies for Self- and Co-Regulation*, Julie Brown, Ph.D., President of the Skills System, LLC
- **November 2020:** *Collaborative Research in IDD and MH with a PCORI Project Update: Reconciling the Past and Changing the Future,* Jessica Kramer, Destiny Watkins, and Micah Peace (Part 1), and Jessica Kramer, Destiny Watkins, Micah Peace, Dr. Joan Beasley, Tawara Goode, Beth Grosso, and Fiorella Calle Guerrero (Part 2)
- **January 2021:** *Sexuality & IDD-MH*, Dave Hingsburger, M.Ed., Director of Clinical and Educational Supports for Vita Community Living Services
- **February 2021:** *Lost in Translation: Lessons about moving research in developmental disabilities into practice and policy*

Yona Lunsky, PhD, Director of the Azrieli Adult Neurodevelopmental Centre and Professor in the Department of Psychiatry at the University of Toronto

- **March 2021:** *"Something's Different" –Concepts of Change in Adults with I/DD*, Julie A Moran, DO, Geriatrician/Internist, Clinical lecturer of Medicine, Harvard Medical School
- **April 2021:** *Aligning our Practices with our Beliefs: (Re) Engaging with Families in the Context of Trauma, Kelly Smith, LCSW*

2020 Virtual START National Training Institute

In light of the COVID-19 pandemic, the Center for START Services hosted a Virtual START National Training Institute (SNTI) from May 4-May 6, 2020, at no cost to participants, as an alternative to its typical in-person annual event. This three-day event featured two keynote presentations with accompanying Q&A sessions, a research panel presentation, the premiere of the new START documentary film ("*Now We Have Hope: The Strength of the START Community*") with a panel discussion, research poster sessions, and an awards ceremony. The virtual SNTI was an enormous success with over 400 participants. All NC START teams submitted poster presentations with NC START West receiving an award.

START Practice Groups

Practice groups are national communities within the START Network organized around START team roles, professional disciplines, and specific topics of interest. They are designed to facilitate active learning communities where members connect with others from across the country in similar roles and remain informed about best practices regarding both START implementation and MH/IDD topics. Each group is facilitated by CSS clinical staff and occasionally features invited speakers and special guests.

As part of the National START Network and learning community, NC START personnel participates in these forums to gain the knowledge and skills needed to improve system capacity. The goal of these groups is to ensure that all START teams have the latest knowledge and technical support to provide evidence-based services. Practice groups meet once monthly (or bi-monthly in the case of Medical Directors). The practice groups include:

- Children's Practice Group, facilitated by Karen Weigle, Ph.D.
- Clinical Directors Practice Group, facilitated by Jill Hinton, Ph.D.
- Clinical Topics Practice Group facilitated by Karen Weigle, Ph.D.
- Resource Center Directors Practice Group, facilitated by Bob Scholz, M.S., LMHC
- Therapeutic Coaching Practice Group, facilitated by Anne Laforce, MA
- Medical Directors Practice Group, facilitated by Karen Weigle, Ph.D. and Jennifer McLaren, M.D.
- Team Leaders Practice Group, facilitated by David O'Neal, MS, and Alyce Benson, LCSW
- Program Director Practice Group, facilitated by Andrea Caoili, LCSW, Alyce Benson, LCSW, and Jillaine Baker, LCSW
- Certified START Program Director Practice Group, facilitated by Jillaine Baker, LCSW

Appendix B: NC START Training Topics and Linkage Agreements by Program

Table 1: NC START Training Topics

Central
IDD, Core Vulnerabilities and the Service System
START Overview with Cardinal
Trauma, Executive Functioning Disorder and Positive Strategies
Trauma Informed Care and Positive Strategies
Medical Diagnoses and IDD
MH/IDD
Executive Functioning and IDD
Overview of IDD and Core Vulnerabilities
Mental Health and IDD Part 1
Mental Health and IDD Part 2
Crisis Intervention team (CIT) Training
Impacts of Trauma on the Brain
START with ART
Therapeutic Supports During COVID
IDD and Core Vulnerabilities
Trauma and Resilience
Common Vulnerabilities and Strategies
PERMA: Positive psychology approaches and wellbeing
A Creative START to 2021
Positive engagement in Congregate Settings
East
Transitioning back to school for students with IDD and complex behavioral needs
Life through a Trauma Colored Lens
Law Enforcement and IDD: Strategies for Success
Sexual Health and individuals with IDD
Executive Functioning
Crisis intervention and De-escalation
Talking about Difficult Things with your Exceptional Child
What is NC START Therapeutic Coaching
Autism Spectrum Disorder (ASD) Overview
Overview of START and Positive Psychology
Collaborating with Law Enforcement
Anxiety and IDD
West
ADHD
Anxiety Disorder, Unspecified
ASD & Executive Functioning Deficits
Autism Spectrum Disorder
Autism Spectrum Disorder & Intellectual Disability, Mild
Autism Spectrum Disorder & Sensory Processing Integration Functioning Disorder
Autism Spectrum Disorder & Social Skills
Autism Spectrum Disorder, Sensory Integration Disorder and Communication
Billing with Confidence Revised
Borderline Personality Disorder
Childhood Onset Schizophrenia
Differential Diagnosis – IDD & Comorbid MH
Disruptive Mood Dysregulation Disorder
Executive Functioning
Fetal Alcohol Syndrome
IDD & Co-Occurring MH Conditions
IDD/MH treatment strategies and service options
Interventions & strategies

Mild ID and Challenges with Executive Functioning
Pancytopenia & PERMA
Psychiatric Medications for Persons with IDD
Psychotic Symptoms
Post-Traumatic Stress Disorder (PTSD)
PTSD, Bipolar DO
Reactive Attachment Disorder or Autism Spectrum Disorder
Recognizing Suicidality in Persons with IDD
Rethinking Disruptive Behavior Disorders

Schizoaffective Disorder
Sensory Integration Dysfunction
Sexuality & IDD
Special Interests in Individuals with ASD
Supporting Children with Virtual Learning
Symptoms of Psychosis in Individuals with IDD
Trauma & Trauma Response
Trauma Informed Crisis Response and Tools