New Hampshire START (NH START)

July 2017 – June 2018

Annual Report

Prepared for

NH START

Prepared by

The Center for START Services

On July 31, 2018

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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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Introduction

This report offers a comprehensive summary of services provided by NH START team for Fiscal Year 2018 (FY18). The analysis includes assessment of outcomes as well as fidelity measures for the START model. Recommendations reflect the results of the analysis and service provision to date.

This report is separated into five sections:

- FY18 Enrollment Trends
- Characteristics of Persons Served (demographics and clinical trends)
- Emergency Service Trends
- START Clinical Team Services
- START Therapeutic Supports

NH START will develop an action plan based on recommendations from the analysis in collaboration with the Center for START Services.

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NH START Program

Program Background

NH START operates throughout the state of New Hampshire and has actively served individuals since May 2010. The NH START program is divided into 10 regions across the state operated by area agencies. While NH START does serve some children, the percentage was less than 8% in FY18. (Figure 2).

The following is a list of NH START programs by region:

Region 1 - Northern Human Services
Region 2 - Pathways/Claremont
Region 3 - Lakes Region Community Services
Region 4 - Community Bridges
Region 5 - Monadnock Developmental Services
Region 6 - Gateways Community Services
Region 7 - Moore Center Services
Region 8 - One Sky Community Services
Region 9 - Community Partners
Region 10 - Community Crossroads

Figure 1: Percent of Active NH START Population by Region

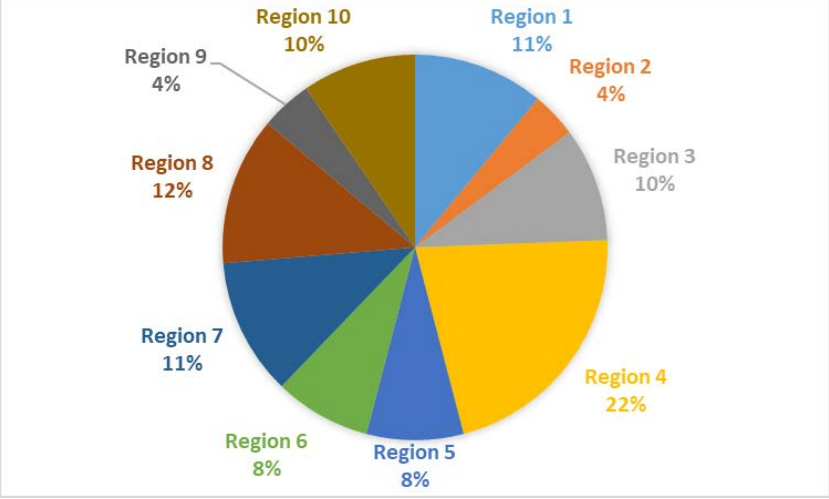
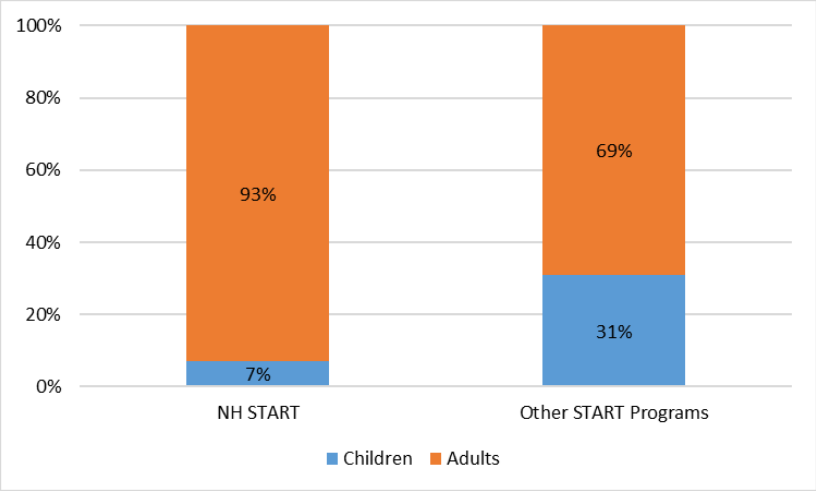
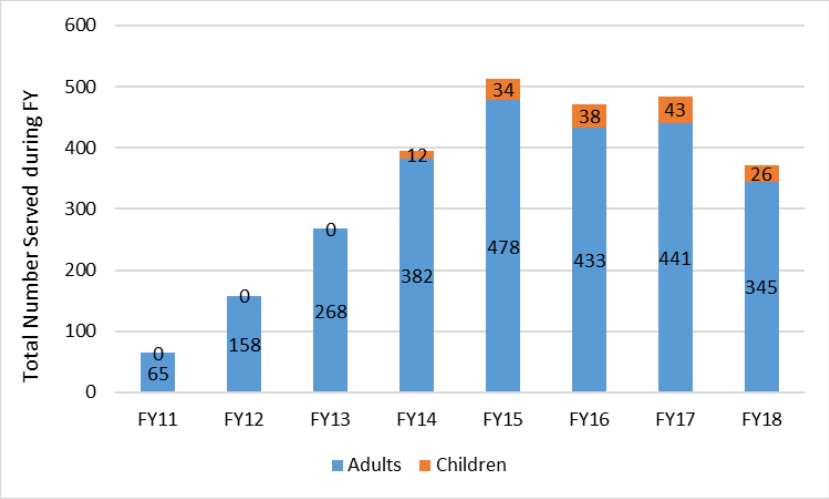


Figure 2: Percent of FY18 START Population by Age Category NH START and Other START Programs



To date, NH START has served a total of 783 individuals since program inception (719 adults and 64 children) with a current active enrollment population of 209. The total yearly census for FY18 was smaller than in the past several years with a total of 371 individuals receiving services during FY18 (figure 3). The low number of children's cases is related to a reduction in funding for children's START services that occurred in 2014-2015. At this time, children's cases continue to be accepted for START services at limited rates. The program is continually advocating for additional funding to fully execute the full range of services to children and their families in New Hampshire. Children are primarily referred to NH START in order to participate in the NH comprehensive multi-modal assessment process, which is a collaboration between NH START and Dartmouth Hitchcock Medical Center.

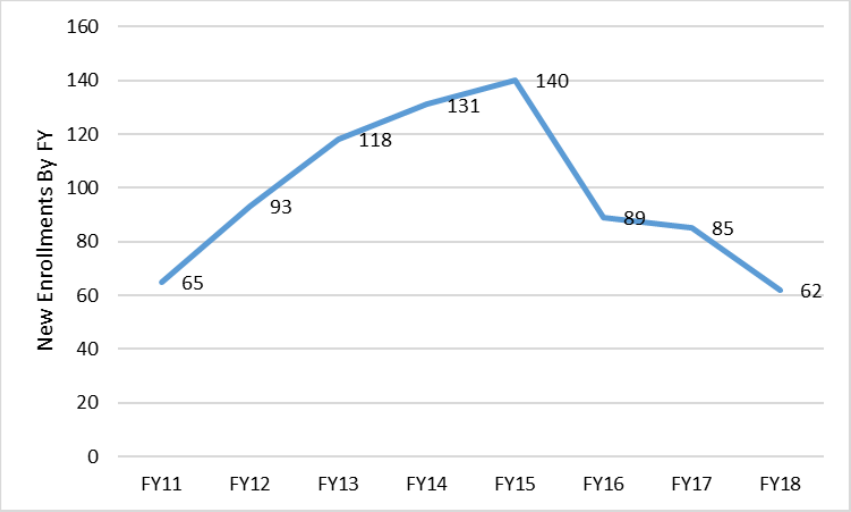
Figure 3: Number of Individuals Served by NH START by Fiscal Year*



*Most Individuals have received services in multiple fiscal years.

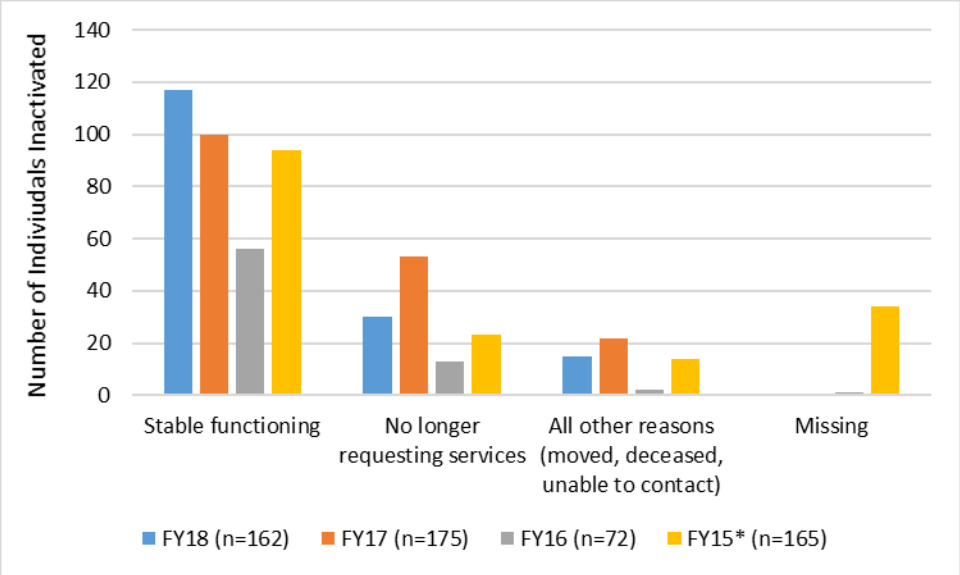
Figure 4 shows the number of newly enrolled individuals in NH START each year since program operations began.

Figure 4: Number of Individuals Enrolled in NH START by Fiscal Year (n=783)



While individuals are not discharged from NH START, they are inactivated once they reach a period of stability or because their situation has otherwise changed (ex: they leave the state). To date, NH START has inactivated a total of 574 individuals. The average length of stay (LOS) in NH START is over 2.5 years for all individuals. For individuals who have achieved stable functioning and discharged in FY18, the average LOS was 3.1 years. This is much longer than the national average of 12 – 18 months.

Figure 5: Reason for Inactivation from NH START by Fiscal Year (n=574)



*includes 14 individuals inactivated in FY14

Summary

- NH START's average length of stay (LOS) over the course of its existence is longer than most START programs, at 2.5 years for all cases and 3.1 for those inactivated due to stability in FY18. Long LOS can have a significant impact on the capacity to enroll new cases.

- The percentage of cases inactivated due to stability was higher in FY18, and the percentage inactivated due to no longer requesting services went down. There were still 19% of cases inactivated due to no longer requesting services in FY18 which remains high (see table 1 A below).

Recommendations

- NH START Leadership team should develop a standard case review protocol, including review of any cases that are active for 18 months or longer. The rationale for overly long stays in services should be evident in the START Plan summary.
- See recommendations in the sections below regarding individuals disengaging from START by "no longer requesting services".

Before discussing specific findings for individuals enrolled in NH START Services in FY18, a review of the previous year recommendations and how they were addressed is included below.

Recommendations from Fiscal Year 2017 Annual Report/Progress

Program Enrollment

- Explore funding options for START In-Home Therapeutic Coaching services for children with the Department of Health and Human Services (DHHS) in NH.
    - *NH START is engaged in an ongoing conversation with DHHS. It is anticipated that as the conversation evolves, other entities within the state will likely be invited to the table to collaborate and formulate a plan to provide In Home Therapeutic Coaching. This will continue into FY18.*
- Review caseloads regularly and inactivate cases when appropriate, allowing capacity to support newly enrolled individuals statewide. Activate again as needed over time per the START model.
    - *This has been an area of concentration for the NH START clinical team. Despite having an average of 3-4 coordinator vacancies throughout the year, the program has provided supports and services to almost 300 individuals in FY18. Due to these vacancies, the need for services has exceeded the capacity of current coordinators and there is a waiting-list for services. The NH START Clinical team has designed a plan to increase movement and eliminate the waitlist in the next fiscal year.*
    - *The NH START program should be examine the LOS of individuals served and devise an action plan that will result in reduced LOS, while maintaining the goal of inactivating cases only when the person has achieved stability.*

Characteristics of Persons Served

- Continue to educate teams and communities regarding IDD/MH and encourage referrals of individuals with diverse developmental and mental health needs.
    - *The NH START program has increased community involvement and training over this year. They have provided training for many new organizations including the NH State Prison, SANE (Sexual Assault Nurse Examiners), the Direct Support Professionals Conference and several vendor organizations across the state. Coordinators have also participated in school transition nights, resource fairs and other community events.*

Emergency Service Trends

- Increase the number of active linkage agreements with community hospitals.
    - *NH START has strengthened its relationships with New Hampshire Hospital, Concord Hospital, Dartmouth Hitchcock and various others but official agreements have not yet been signed.*
    - *As suggested in the report, NH START leadership should work with their Program Facilitator to confer with other START teams who have been successful in executing linkage agreements with hospitals, since this is a common challenge.*
    - *While linkages with these entities is important, the program should also assure that a plan is put in place to assure enhanced collaboration and linkage with community providers, especially those that interface with the START Resource Center on a regular basis.*

- Stronger, more active linkage agreements with the community mental health centers is needed.
    - *Linkage agreements with several community mental health centers have been strengthened as evidenced by increased collaboration on individual cases.*

- Improve the accuracy of SIRS data collection regarding crisis response statewide.
    - *The NH START leadership has been working with all staff to improve data entry and there have improvements in this area in FY18. This remains an area for additional work over the coming year.*

- Face-to-face crisis evaluations should be the norm when a crisis call is received.
    - *The number of in-person crisis evaluations has increased this year. As families, vendors and Area Agencies become more comfortable accessing START on-call support, the frequency of calls are expected to increase. One improvement noted is that START crisis support is being contacted more often when an individual accesses emergency services (MH crisis support, Hospital ED, legal involvement). This can be attributed to wider knowledge of the availability of START crisis supports and well as the Bureau of Developmental Services (BDS) formalized protocol regarding individuals who are admitted to a hospital for more than a 24-hour period.*
    - *A target for in person crisis assessments should be at or above 70% of crisis contacts, so this will be a goal for the coming year.*

START Clinical Services

- Increased collaboration between Clinical team leadership and Center leadership teams.
    - *START leadership (including clinical and resource center) meets weekly to increase collaboration and improve communication between both parts of the program. The combined leadership team also meets periodically for full-day retreats to create a cooperative vision for the program moving forward.*

- Continue to improve timeliness and accuracy of data collection throughout NH START.
    - *The NH START Clinical Team has improved the timeliness and accuracy of data collected. By year-end demographic data was 100% complete, and other data elements were greatly improved. This is a continued area of growth for the upcoming year.*

- Increase opportunities for cross training among START Coordinators, who all have specific IDD/MH expertise.
    - *The NH START Clinical Team has become a strong, cohesive group over this past year. In an effort to truly become a statewide program with full back-up supports, several efforts were made to strengthen collaboration between coordinators, including retreats, several workshops (goal-writing, peer QA checks, crisis plan writing) and increased information sharing through daily triage meetings. On-call*

services were fully implemented this year, resulting in increased collaboration among coordinators to secure best outcomes and increased capacity to support START enrollees.

- Increase the attendance of community members at Clinical Education teams (CETs) monthly.
    - *This year the NH START has made a concerted effort to increase participation at Clinical Education Team Meetings. Each coordinator was asked to invite one non-team member to each training and virtual attendance was made available. Upcoming CET topics have been distributed to prospective attendees and program partners to increase interest.*

- Increased leadership and management training for Clinical Team Leaders.
    - *NH START Clinical Team Leaders participated in the University of New Hampshire Women's Leadership workshop and have regularly attend the Center for START Services Team Leader Practice Group meetings.*

- Look to increase overall outreach contacts with active enrollees. On average about 90% or higher of active enrollees should receive outreach from their START Coordinator.
    - *NH START Coordinators have increased outreach services to over 80% of enrollees for this FY18 and will work to achieve the benchmark target of 90% or more in FY19.*

- Continue to address numbers of enrollees with active CSCPIP's. This needs to be in line with national standard, which is a minimum of 85%.
    - *NH START Coordinators have continued to work toward meeting program standards in this area. At the time of this report, they are meeting standards regarding completion rates of initial plans. However, the NH START program data showed 67% of enrollees have an updated/current crisis plan.*
    - *See recommendations below under section addressing START planned services. The NH START leadership will need to develop strategies to achieve compliance in this area, and to follow a plan to maintain the national standards moving forward.*

<u>START Therapeutic Resource Center Services</u>

- Develop a portfolio of testimonies from guests, family members and team members, written and video.
    - *As part of the 2018 START National Training Institute celebration, testimonials were obtained from several families and individuals served through NH START. A portfolio has been developed, and includes positive feedback regarding guest, family member and support staff experiences.*

- Continue to focus on improvement of therapeutic goal development for guests with training of START Coordinators and Center leadership.
    - *The NH START leadership created a quick reference of sample goals and objectives, provided a didactic training on goal writing, held interactive goal-writing workshops in which a BDS liaison participated and have implemented a clinical review of goals prior to each admission. Center leadership have become more involved in clarifying the intent of goals and objectives and providing active input and feedback.*

- Increased linkage agreements between the Resource Center and local community organizations and state resources.
    - *Given several leadership transitions this year, the establishment of linkage agreements with Resource Center partners has not occurred and remains a goal for the upcoming year. The NH START leadership should create an action plan and set target dates to ensure linkage agreements are secured in FY19.*

- Increase utilization of emergency beds at the Center.
    - *This year NH START supported 49 individuals through our emergency beds, with an occupancy rate of over 76%. This an increase over both FY16 and FY17.*
    - *There needs to be continued efforts and a plan developed to reach the target of 85% bed occupancy for both planned and emergency admissions. This should include discussions during regular triage meetings and clinical review of cases.*

- Increased utilization of the Resource Center by regions that have underutilized the Center.
    - *There was an increase in utilization by regions that have not used the Resource Center during the previous FY17. This continues to be an area of growth and a goal in the coming year. This will be tracked and reported in FY19 quarterly and annual reports.*

- Ensure that discharge summaries are written in a timely manner and distributed to teams following discharge from planned and emergency stays at the Center.
    - *This continues to be an area of growth for the NH START Resource Center. When new leadership for the Resource Center is established, this will be a primary focus.*
    - *In order for the program to meet expectations for START program certification, an improvement in this area must be made. Discharge summaries should be consistently completed as discharge planning is an integral piece of transition planning and demonstrates continuity of care. Discharge summaries should be completed and distributed within 24 hours of discharge from the START center.*
    - *Recommendations regarding compliance can be found in the Therapeutic Supports section of the report.*

- Increased leadership and management training provided to NH START Resource Center leadership.
    - *Team Leaders were afforded the opportunity to attend the START National Training Institute held in Boston this past year. Additionally, they have received increased training support from the clinical team and have also received in-milieu coaching from the NH START clinical director and the Center for START Services Resource Center Services Director.*

Findings

Following is an analysis of enrollment, demographic and service outcome data for NH START for FY18 (July 1, 2017-June 30, 2018).

Enrollment trends, characteristics of persons served, emergency service trends, and service outcomes of those served by NH START are based on data entered into the START Information Reporting System (SIRS). When noteworthy, adult elements are compared to national START trends. NH START served so few children in FY18 that trends for this cohort could not meaningfully be compared

Section I: FY18 Program Enrollment

Data below reflect all individuals served by NH START during this reporting period.

Table I.A: FY18 Census Summary

NH START	FY18 (n=371)	
Variable	Children	Adults
Total Served during reporting period N (%)	**26 (7%)**	**345 (93%)**
FY18 New Enrollments	9	53
Individuals inactivated	**16**	**146**
Stable functioning	11 (69%)	106 (73%)
Moved out of START region	-	8 (5%)
No longer requesting services	3 (19%)	27 (18%)
Inappropriate for services	-	1 (1%)
No contact	2 (12%)	1 (1%)
Deceased	-	3 (2%)
Active Caseload at the end of reporting period	**10 (5%)**	**199 (95%)**

Table I.B: Source of Referral: Trends Over Time
*These numbers include the children's referrals (n=9), 90% of which were also from case managers.

Variable (N)	FY18* (n=62)	FY17* (n=85)	FY16* (n=89)	National Adult START Trends (n=1941)
Referral Source (%)				
Case Manager	94%	89%	89%	63%
Emergency Department/mobile crisis	2%	-	-	8%
Family Member	3%	-	2%	6%
Residential/Day Provider	-	-	1%	11%
Hospital/ID Center	-	-	-	4%
Mental Health Practitioner	-	2%	1%	2%
Other (Behavior Analyst, law enforcement, schools)	2%	2%	3%	6%
Missing	-	6%	3%	-

Table I.C: Reasons for enrollment (FY18 new enrollments only)-More than one option can be selected

Variable (N)	NH START (n=62)	National Adult START Trends (n=1941)
Most Common Reasons for Enrollment (%)		
Aggression	68%	81%
Family Needs Assistance	58%	35%
Risk of losing placement	21%	19%
Decreased Daily Functioning	53%	22%
Dx and Treatment Planning	61%	18%
Mental Health Symptoms	76%	52%
Leaving Unexpectedly	21%	20%
Suicidality	16%	18%
Self-Injurious Behavior	24%	28%
Sexualized Behavior	11%	11%
Transition from Hospital	16%	8%

For children referred, the frequency of aggression was 88% in NH compared with 90% for children nationally.

Summary

- Case managers from NH area agencies are almost the sole source of referrals to the NH START program. While most programs receive the majority of referrals in this way, individuals referred to NH START must be on the IDD waiver or ABD waiver and approved for services through one of NH's regional area agencies. This leads to the majority of referrals coming from Case managers as they often have access to information regarding eligibility.
- There were a few referrals to NH START that came directly from hospitals. While the percentage of referrals received in this way is limited, it is important to note, as it may be a reflection of the recent linkage and outreach efforts on the part of NH START as well as the program's transition to 24-hour crisis response.
- Though aggression is still a primary reason for referral, it is less frequently reported than other START teams (68%). Also, the reported referral rates for *needing diagnostic clarification and treatment planning* and *mental health symptoms* is much higher for NH START when compared to national START. These data may be a reflection of the increased understanding of NH case managers of the kind of help that can be obtained when a person is supported by a START program.
- While the primary reason for inactivity was stability, 18% of cases were made inactive due to no longer requesting services. It is an important aim to study factors impacting disengagement and find ways to increase retention of anyone who has been referred and is likely to benefit from START.
- It was also found that cases remain active in NH START longer than in other programs. NH START cases remain active for 2.5 years on average, and for 3.1 years for cases inactivated due to stability.

Recommendations

- Ongoing efforts should continue to maximize enrollment of new cases within the capacities of the program.

- Expanding the scope and target for linkage agreements may help to increase referrals from other sources than case managers and increase capacity of more parts of the community service system supporting people with IDD and co-occurring behavioral health issues.
- The NH START program should develop a survey for all stakeholders including individuals and teams actively engaged in services. Stakeholder surveys can assist the program with understanding the reasons behind dis-engagement from services and other issues that may present.

Section II: Characteristics of Persons Served

Demographics

Section II of this report provides demographic and diagnostic trend data for all individuals served by NH START (N=371) during FY18 (July 1, 2017-June 30, 2018). There are no significant differences in the demographics of active individuals in FY2018 compared to previous fiscal years. When relevant, the NH START population is compared to other START programs nationally.

Table II.A: Age, gender, race, level of ID, and living situation for NH START enrollees (n=371)

	FY18 (n=371)		Other START Programs	
Variable	Children	Adults	Children	Adults
N	26	345	886	1941
Mean Age (Range)	13 (7-17)	35 (18-77)	14 (6-17)	31 (18-80)
Gender (% male)	85%	60%	76%	61%
Race				
White/Caucasian	85%	94%	57%	64%
African American	8%	1%	26%	23%
Asian	-	1%	4%	2%
Other	-	2%	10%	6%
Unknown/Missing	8%	2%	5%	5%
Ethnicity (% Hispanic)	4%	1%	15%	13%
Level of Intellectual Disability (%)				
No ID/Borderline	12%	12%	13%	7%
Mild	27%	59%	35%	48%
Moderate	27%	23%	29%	31%
Severe-Profound	0%	2%	9%	10%
Not specified in records	35%	4%	12%	4%
Missing	0%	1%	2%	1%
Living Situation (%)				
Family	96%	34%	87%	43%
Enhanced Family Care/Foster Family	-	30%	3%	5%
Group Home and Community ICF/DD	4%	15%	4%	31%
Independent/Supervised	-	13%	1%	12%
Psych. Hospital/IDD Center	-	3%	3%	5%
Other (Jail, Homeless, "Other")	-	4%	1%	3%
Missing	-	1%	1%	1%

Summary

- NH START provides support to a slightly less racially and ethnically diverse population than other START programs, but this is consistent with the racial and ethnic makeup of the region. While this may be the case, there are some areas of larger cities such as Manchester that have a concentration of immigrant populations. It is important this is this is recognized that that culturally competent outreach efforts are put into place. Each family, provider, and individual have a unique cultural identity that should be taken into consideration during treatment planning and service provision
- The average ages of children and adults served in NH START is similar to the national START trends.
- NH START enrollees include 85% males, somewhat higher than the 61% rate reported in the national data set.
- A lower percentage of the individuals served in NH START are diagnosed with Mild ID or have borderline or no ID, as compared with national data reports (39% vs. 55% respectively).
- Half as many NH START program enrollees are residing in congregate care settings as found with other START programs (15% vs 31%). Alternatively, almost every child and over one third of adults they serve are living in a family setting. This is related to the NH state service system's preference to promote home like living situations, and to minimize use of congregate care settings.

Recommendations

- NH START should review and enter the level of disability for the child cases currently listed as not specified in records at intake as either no ID or other designation, as this would be important information contributing to treatment planning, as well as programmatic planning.
- The NH START program should assure that their staff receive training in cultural competency and that this is an active component of START service delivery. There are resources available through the Center for START Services and these can be accessed through collaboration with the program's CSS project facilitator.

Mental Health and Chronic Health Conditions

Table II.B: NH START enrollees with mental health conditions reported at intake

NH START	FY18 (n=371)	
Variable	Children	Adults
N	26	345
Mental Health Conditions (%)		
At least 1 diagnosis	77%	94%
Mean Diagnoses (range)	1.8 (1-5)	2.2 (1-7)
Most Common MH Conditions (%)		
Anxiety Disorders	25%	27%
ADHD	30%	28%
ASD	55%	23%
Bipolar Disorders	10%	21%
Depressive Disorders	10%	35%
Disruptive Disorders	15%	12%
OCD	10%	13%
Personality Disorders	0%	13%
Schizophrenia Spectrum Disorders	5%	12%
Trauma/Stressor Disorders	30%	30%

Figure II.A: Frequency of most common mental health conditions for enrolled children (trends across START)

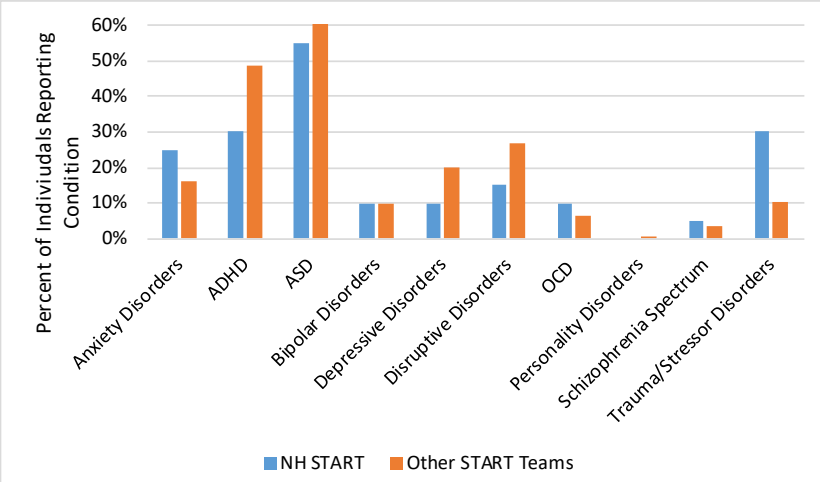


Figure II.B: Frequency of most common mental health conditions for enrolled adults (trends across START)

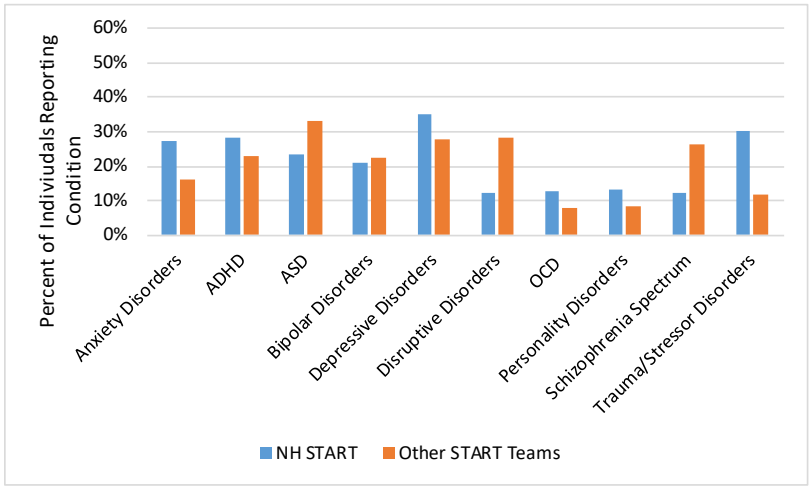
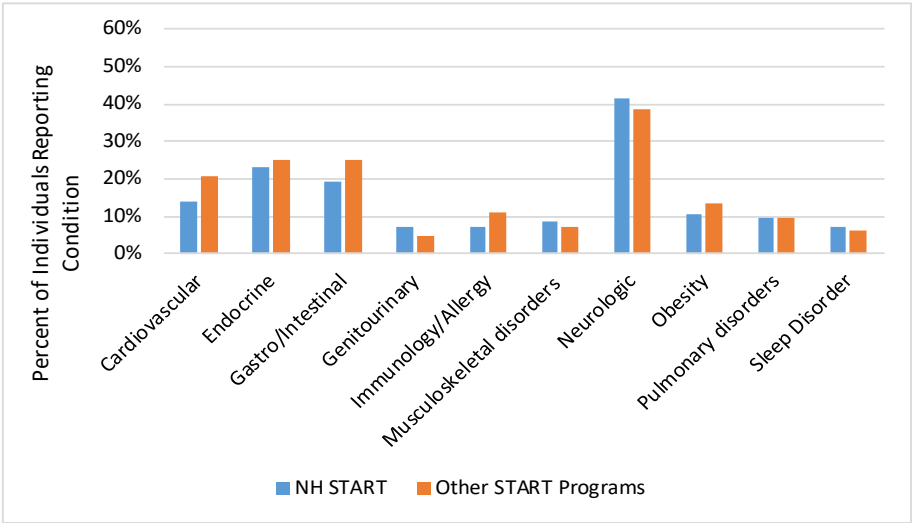


Table II.C: NH START enrollees with chronic medical conditions reported at intake

NH START	FY18 (n=371)	
Variable	Children	Adults
N	26	345
Medical Diagnosis (%)		
At least 1 diagnosis	50%	74%
Mean Diagnoses	1.8 (1-6)	2.0 (1-10)
Most Common Medical Conditions (%)		
Cardiovascular	Too Few	23%
Endocrine		20%
Gastro/Intestinal		28%
Genitourinary		3%
Immunology/Allergy		9%
Musculoskeletal		9%
Neurologic		39%
Obesity		14%
Pulmonary disorders		6%
Sleep Disorder		10%

Figure II.C: Frequency of most common medical conditions for enrolled adults (trends across START)



Summary

- The mental health conditions identified at intake include slightly higher rates of anxiety and depressive disorders, and lower rates of psychosis and bipolar disorders. This seems to be a pattern seen in well-established START programs, where the ongoing efforts of START to increase the capacity in the system of care leads to a better understanding of how these conditions present in the population. The NH START program also has access to national experts from the Center for START Services at the University of New Hampshire and Dartmouth Hitchcock Medical Center. CSS staff are active participants at NH START CETs, where diagnostic and treatment discussions and trainings often occur with community partners.
- People with IDD are known to suffer from health problems more than individuals with a neuro-typical history, and frequently have missed medical issues. High rates of comorbid medical conditions were reported for the NH START enrollees as expected. These rates still may be low when compared with research regarding some conditions such as GI issues, that likely impact 40-50% or more of individuals with IDD and mental health conditions.

Recommendations

- Continue the positive efforts made to increase the system's capacity in understanding that problems like anxiety and depression and trauma are the most common psychiatric conditions through CETs and other community trainings.
- Consider adding some additional specific training opportunities that focus on how common GI issues are children and adults with IDD, and how these conditions (i.e. constipation and Gastro Esophageal Reflux Disease or GERD have been linked to irritability and aggression and may provoke a clinical picture that mimics an acute psychiatric event.

Section III: Emergency Service Trends

Table III.A: Emergency Service Utilization

Variable	Children	Adults
N	26	345
Psychiatric Hospitalization	**6 (23%)**	**51 (15%)**
Prior to enrollment, N (%)	1.7 (1-3)	1.6 (1-6)
Mean Admissions (range)		
During START, N (%)	**3 (12%)**	**24 (7%)**
Mean (range)	2.0 (1-3)	1.6 (1-4)
Average length of stay (days)	14 days	30 days
Emergency Department Visits		
Prior to enrollment, N (%)	**6 (23%)**	**102 (30%)**
Mean Visits (range)	2.0 (1-4)	2.2* (1-50)
During START, N (%)	**1 (4%)**	**47 (14%)**
Mean (range)	4 (4)	1.8 (1-6)

*There is one adult with 50 ED visits documented. The range omitting these outliers is 1-20. The calculated mean excludes this outlier.

The figures below show the change in frequency between pre- and post-enrollment emergency service utilization for NH START enrollees.

Figure III.A: Change in frequency of pre and post START enrollment emergency service utilization (children)

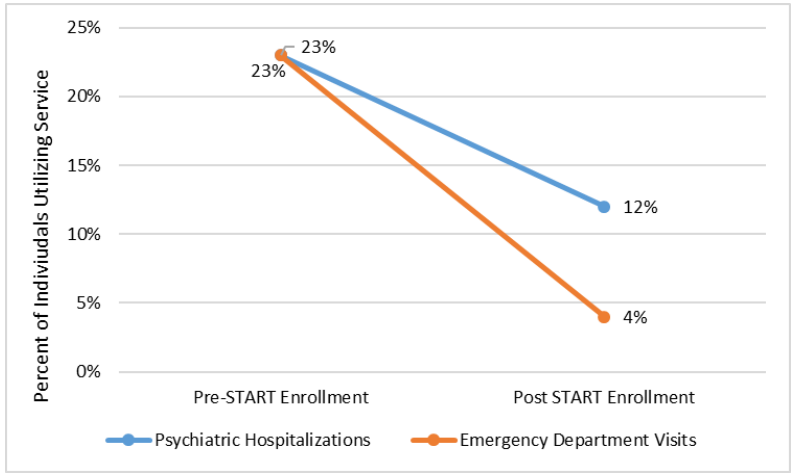
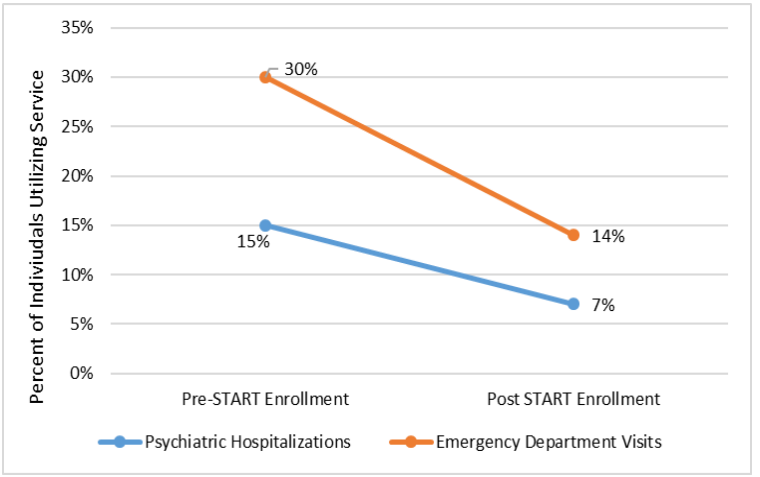


Figure III.B: Change in frequency of pre and post START enrollment emergency service utilization (adults)



Summary

- The change in ED and psychiatric hospitalization rates pre to post NH START enrollment is very encouraging for both children and adults. These data are consistent with national START trends in decreases in emergency service use when enrolled in START.

Recommendations

- Continue to provide outreach and other planned interventions, to reduce emergency services use, while adding to the capacity of community partners to provide more proactive care in ways that promote physical and mental wellness for all individuals with IDD in the Region.

Section IV: START Clinical Services

Based on a tertiary care approach to crisis intervention, START service measures fall into three crisis intervention modalities:

Primary (improved system capacity): Clinical Education Teams (CETs), community education, training, and system linkage,

Secondary (specialized direct services to people at risk of needing emergency services): Intake and assessment activities, Comprehensive Service Evaluations (CSE), outreach, clinical and medical consultation, and Cross Systems Crisis Prevention and Intervention Planning (CSCPIP); planned therapeutic supports (Resource Center and Therapeutic Coaching) 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 (includes emergency therapeutic supports).

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 NH START team members since program operations began. Primary START services include system linkages, education and community training. These services are part of the plan to improve the capacity of the system as a whole so that improvements are effective and sustainable over time. Over the last year, the NH START team has engaged the community to provide training and education around the unique needs of individuals with IDD and co-occurring behavioral health issues and continues to engage the system to become active participants in the START learning community.

Table IV.A: Community training activities

NH START	FY18
Number of Activities (N)	
Community linkage/affiliation	7
Community-based training	7
Host Advisory Council Meeting	4
Provided Training (N)	
Day provider	5
Emergency services	-
Family	2
Other	26
Physician/medical personnel	1
Residential provider	3
School	1
State facilities (state hospitals, developmental centers)	-
Therapist/mental health providers	3
Transition Support/Planning-Developmental Center	-
Transition Support/Planning-Psychiatric Hospital	2
Total Community Outreach/Training Episodes (N)	58
Total Linkage/Collaboration Agreements Completed Since Program Inception (N)	10
Total Clinical Education Teams in FY18 (N)	12

In addition to the above reported specific training and linkage activities, a number of more informal outreach efforts were made. These included providing community partners with information about START and issues pertaining to the population served. More information about these activities can be obtained from the NH START Program Director.

The following is a list of some of the training provided to the community as part of the primary services provided by the region during FY18.

Table IV. B: Clinical Education Teams in FY18

Date	Title/Training Topic	Number in attendance
7/17/17	PTSD	22
8/8/17	Language Fluent Aphasia	18
9/26/17	Autism and Anxiety	14
10/2/17	Catatonia in IDD	23
11/14/17	Substance Use Disorders and IDD	13
1/22/18	Elimination Disorders	18
1/23/18	Management of delusional Thoughts in individuals with IDD	13
2/20/18	Trauma: Impact on Attachment, Cognition, Emotions & Behavior - Fetal Alcohol Syndrome	16
3/27/18	Parkinson's Disease and its Progression	18
4/2/18	Sexuality and IDD	24
5/15/18	Schizophrenia and Dementia	17
6/12/18	Fragile X and Aging	14

National START Practice Groups

As part of the national START network and Professional Learning Community, NH START personnel participate regularly in national practice 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 ensure that all START teams have the latest knowledge and technical support to provide evidence-based services. 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.
- National START Online Training Series, offered by the Center for START Services to START programs
- The START National Training Institute chaired by Joan B. Beasley, Ph.D., Director of the Center for START Services

Summary

- This year NH START expanded training support within the system of care and provided training series for several vendors and program partners, including the NH State Prison, Becket Family of Services and at the Direct Support Professionals Conference. Coordinators also participated in school transition nights and resource fairs.
- The team sought to increase attendance at Clinical Educational Trainings and did see an increase in attendance. The increased community presence has sparked interest from other entities and NH START will be working on promoting continued growth in this area.
- The NH START Program made a concerted effort this reporting period to get more linkage agreements with hospitals with limited success.
- There are currently 10 completed linkage agreements that the NH START program has entered into with community stakeholders. Given the age of the NH START program, they do not meet fidelity in this area at this time.

Recommendations

- NH START has very low numbers of linkage agreements. It is recommended that the NH START leadership develop a plan of action to address this concern and set a target for completing additional linkages by the close of FY19. The diversity of current linkages should also be reviewed, and benchmarks set by the program, in consultation with the Center for START Services should be developed.
- Linkage agreement and relationship development should be focused on community stakeholders who interface with START regularly. These stakeholders might include community MH providers, area agencies, non-profits, primary care and psychiatric care management agencies and START advisory council members. While the execution of linkage agreements with hospitals is certainly important, the program should also recognize the value in relationship development with a wide array of community service providers and stakeholders.
- Continue efforts to increase and track attendance at CETs, to expand the effects of this primary intervention tool, to increase system capacity in the care of people with IDD who have behavioral health needs.
- Develop a system for more closely tracking all primary services and identify all linkages, outreach occurrences, training topics and individuals attending any community (versus individually based) trainings.

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.

All START programs offer the following planned, secondary services and time spent on these activities is 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 the START Coordinator provides informal education or outreach to the system of support related to general issues or those specific to the individual. 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*: Consultations provided by the Clinical Director with community team members who support individuals.
- *Medical Consultation:* 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.
- *Facilitation of Planned Therapeutic Supports (Resource Center, Therapeutic Coaching)*: 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.

Table IV.C shows the percent of individuals enrolled in the state who received planned START services during the year. 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.

Table IV.C: Provision of Planned START Clinical (Coordination) Services

NH START	Children	Adults
N	26	345
Utilization of Planned Services (% of Individuals)		
Outreach	81%	84%
Intake/Assessment	85%	85%
CSCPIP	35%	59%
Clinical Consultation	85%	89%
Medical Consultation	58%	39%
Therapeutic Supports	0%	48%
Crisis Follow-Up	15%	26%

START Intake and Assessment

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

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

START Tools	Tool was completed (Active)	Up-to-date
START Action Plan	96%	89%
Aberrant Behavior Checklist (ABC)	95%	83%
Recent Stressors Questionnaire (RSQ)	96%	96%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	91%	67%
Comprehensive Service Evaluations (CSEs) Completed	17%	N/A

Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item informant report, psychopathology rating tool designed specifically for use with individuals with IDD (Aman, Burrow, & Wolford, 1997). The ABC is administered to START service recipients at intake and again at 6-month intervals.

The ABC has been reported in the literature as an *outcome measure*, having demonstrated sensitivity to detecting changes in psychopathology ratings over time. The ABC is used to determine if the provision of START services is associated with reduced psychopathology ratings over a 6-month or greater period of time. When using the ABC, the authors suggest use of the subscales, and not a total scale score. Subscales were identified via a factor analytic process, and three of these have been reported in the literature as sensitive to treatment effects, including the *Irritability*, *Hyperactivity* and *Lethargy* scales so these are reported below for FY2018 NH START enrollees.

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=254). The average time between the two administrations used in this analysis was 28 months. Results show that average scores decreased as shown in Table IV.F.

Table IV.E: ABC Analysis

NH START (N=254)	Percent with Improvement	Mean Score		t Stat	P(T<=t) one-tail
		Initial	Most Recent		
Hyperactivity/Noncompliance	60%	16.12	13.51	3.98	<0.00
Irritability/Agitation	56%	17.59	14.88	4.21	<0.00
Lethargy/Social Withdrawal	53%	10.00	8.33	3.04	<0.00

Alpha=0.05

Summary

- Enrollees received a wide range of planned START services; however, reported rates for some of the services were low, including updating of CSCPIPs, and ABCs. Documented time spent on CSCPIP related activities (35% of cases) appears low given the rates of CSCPIPs completed.
- The NH START program is meeting standards in the area of initially completed START tools and plans. However, some of these plans not current.
- Individuals served by NH START demonstrated reduced measures of psychopathology as evidenced by the ABC subscale scores reported. This is consistent with data from other START programs.
- Though reduced ABC scores can be a very useful outcome measure, other factors may also be important in determining the effectiveness of interventions, including helping people remain with natural supports. Other data suggest that individuals served in NH START demonstrating improved functioning based on the large reduction in ED visits and psychiatric inpatient stays noted above. Collectively, these outcome measures suggest the START model is helping significant numbers of enrollees.

Recommendations

- The NH START team should develop an action plan to increase the percent of enrollees with an up to date START Plan, ABCs, and CSCPIPs and outreach services to be in line with national START fidelity standards by the second quarter of FY19.
- CSCPIP time tracking is lower than the percentage of completed and updated plans documented. This may be a data entry issue, or it could present an incorrect understanding of the crisis planning process. START CSCPIPs are organic, evolving documents, which are facilitated by the START coordinator with the full commitment and participation of the individual's team. It is important for the NH START leadership team to examine the reason for in-congruency and assure that clinical team members are engaging the system of support for enrollees.
- NH START should continue to collect regular data on outcomes associated with improved functioning and service effectiveness. As more components are being used, even greater reductions in psychopathology measured by the ABC would be an important indicator of the significance of these additions.

Tertiary Services

Emergency interventions provided during a crisis

NH 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 NH START team that requires immediate triage and response, likely resulting in an in-person 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.

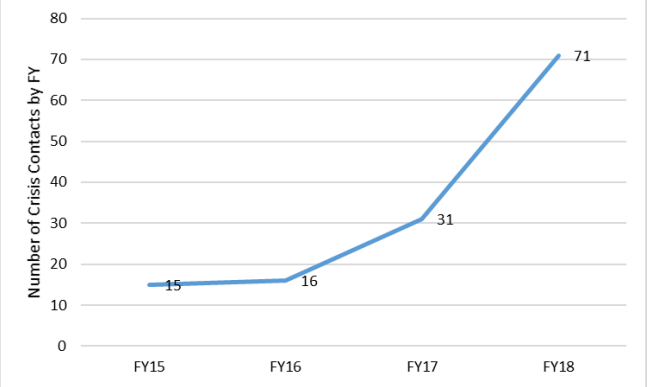
Crisis Contacts

Table IV.F: FY18 Crisis Contacts

**No crisis calls received for children during reporting period.

NH START	FY18
Variable	Adults
Crisis Contacts Number of Individuals with a contact	 50
Number with Crisis follow-up	90
Number of Crisis Contacts	71
Range of Contacts	(1-6)
Frequency of calls with each type of Intervention N (%) In-Person Phone Consultation Missing	 27 (38%) 43 (61%) 1 (1%)
Average Length of In-Person Intervention	3.3 hours
Crisis Disposition for each crisis contact N (%) Maintain Setting Psychiatric Hospital Admission Emergency Department Medical Hospital Admission START Therapeutic Services Crisis Stabilization Other (Incarcerated, Referral to services, "Other") Missing	 39 (55%) 2 (3%) 8 (11%) 1 (1%) 13 (18%) - 5 (7%) 3 (4%)

Figure IV.A: Acute Crisis Contact Trends per FY



Summary

- The number of crisis contacts more than doubled since FY17.
- The increase in crisis contacts is likely related to NH START having started to engage in face-to- face crisis assessments this year (a new component of the crisis prevention and intervention services of the program). Specific outreach efforts were also made in FY18 to increase use of this support by families and vendors, as well as hospitals and other community partners.
- One area of improvement is that NH START crisis support is being contacted more often when an individual accesses emergency supports (MH crisis support, Hospital ED, legal involvement). This can be attributed to wider knowledge of the availability of START crisis supports and well as a BDS formalized protocol regarding individuals who are admitted to a hospital for more than a 24-hour period.
- The percentage of in-person assessments increased this year but remains low (38%). It is expected that about 70% of crisis contacts will occur in person. The low rate reported for FY18 is believed to be due to the newness of the service. As families, vendors and Area Agencies become more comfortable accessing on-call support, the NH Team expects more face-to-face evaluation will occur. However, the rate of only 55% *maintain setting* is lower than usually reported for START crisis contacts and will likely increase with more in person assessments.

Recommendations

- Continue outreach efforts that increase collaborations and accessing of START crisis supports from community systems serving START enrollees.
- A plan needs to be developed in order to guide team leaders and coordinators in identifying those individuals who would benefit from an in-person assessment, given the low rates reported for FY18.
- NH START team should review crisis disposition data and assure accuracy.

Section V: START Therapeutic Services

Resource Center

The following table reflects utilization of the START Resource Center. The program has six 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 due to ongoing behavioral health concerns. Depending on the needs of the person and his/her family, the frequency and length of planned Center admissions may vary but average about 3 days per admission. The other two beds are designated for emergency admissions, which serve adult enrollees experiencing acute crises. Emergency admissions are longer and average about 19 days, during which time, guests received assessment and individualized intervention and discharge planning.

Table V.A: Planned Center-Based Supports

NH START	FY17	FY18
Number of individuals admitted	85	85
Total number of admissions	242	221
Range of days	1 to 5	2 to 7
Avg LOS (days)	3	3
Total time spent in resource center (days)	804	767
Number of individuals with more than 1 admission	60	55
Percent of individuals with more than 1 admission	71%	65%
Occupancy Rate (3 beds)	73%	70%

Table V.B: Emergency Center-Based Supports

NH START	FY17	FY18
Number of individuals admitted	35	40
Total number of admissions	43	47
Range of days	3 to 30	1 to 30
Avg LOS (days)	16	19
Total time spent in resource center (days)	653	956
Number of individuals with more than 1 admission	6	6
Percent of individuals with more than 1 admission	17%	15%
Occupancy Rate (3 beds)	60%	87%

Summary

- The occupancy rate for planned admissions is 70%. The program should aim for a 75% utilization rate for planned admissions in the coming year. The program has improved its mechanism for scheduling planned admissions, which should increase utilization in the upcoming year.

- Trends in emergency Resource Center admissions are meeting START fidelity standards at this time. Utilization rates have increased from 60% in FY17 to 87% in FY18. Additionally, recidivism rates (individuals with more than one admission) and the average length of stay (19 days) is in line with national START standards.

- Another focus this year has been to improve the quality of goal setting and discharge planning. A clinical review of goals was conducted prior to each admission. Center leadership have become more involved in clarifying the intent of goals and objectives and providing active input and feedback.

- While not referenced in the data above, the NH START program has identified that discharge planning and summary writing is an area of growth needed in the coming year. Discharge planning at the START Center provides opportunities for the guests' teams learn what has been effective at the Center and receive support with generalizing new interventions and skills acquired into the person's community settings. It is an integral factor in promoting stability over time. At this time, the NH START program is not meeting fidelity standards in this area, which require that discharge summaries be completed and distributed to the guests' teams within 24 hours of discharge from the Center.

Recommendations

- Continue efforts to increase Resource Center utilization, especially for planned admissions. The NH leadership team should track this monthly and discuss strategies to ensure ongoing growth in this area.
- NH START must develop strategies and outline actions steps to assure that discharge summaries are completed and distributed in a timely manner. These summaries are an important tool that coordinators share and use to conduct outreach with individuals and their systems of care to promote positive outcomes.

Conclusions and Recommendations for Fiscal Year 2019

Conclusions

NH START has served a large number of individuals in need over the FY including a total of 26 children and 345 adults. There has been concern however, that enrollees remain active in NH START much longer than other START programs. Though a large number of people received START services, the number of newly enrolled cases was lower this year than in past years.

During FY 2018, responding in person to crisis contacts was initiated as a new service, and crisis contacts nearly doubled. Work has been done to educate system partners to increase use of crisis services and to increase in person assessments.

NH START services resulted in improved outcomes as evidenced in the reduced frequency of ED visit and inpatient psychiatric hospitalizations from before and after enrollment, and reductions in Aberrant Behavior Checklist noted following receipt of START services.

During this fiscal year, the use of planned and emergency Resource Center bed days was increased, and new leadership for this service has been identified, with need to continue the work to achieve optimal utilization. The NH START has continued to provide comprehensive multidisciplinary evaluations for children and adults through the Dartmouth-Hitchcock team.

NH START has been centralized for about 3 years and will be focused on program certification in the upcoming year. Some areas to be addressed include: scheduling and securing certification for coordinators and other staff (10/13 current staff are certified and there were 5 vacant positions as of this writing), significantly expanding the number of linkage agreements and outreach work with community partners, increasing the use of planned bed days in the NH START Resource Center, and addressing issues related to admissions and discharge summaries for Resource Center guests,

Recommendations for Fiscal Year 2019

Program Enrollment

- Ongoing efforts should continue to maximize enrollment of new cases within the capacities of the program.

- Expanding the scope and target for linkage agreements may help to increase referrals from other sources than case managers and increase capacity of more parts of the community service system supporting people with IDD and co-occurring behavioral health issues.
- The NH START program should develop a survey for all stakeholders including individuals and teams actively engaged in services. Stakeholder surveys can assist the program with understanding the reasons behind dis-engagement from services and other issues that may present.

Characteristics of Persons Served

- Demographics
  - NH START should review and enter the level of disability for the child cases currently listed as not specified in records at intake as either no ID or other designation, as this would be important information contributing to treatment planning, as well as programmatic planning.
  - The NH START program should assure that their staff receive training in cultural competency and that this is an active component of START service delivery. There are resources available through the Center for START Services and these can be accessed through collaboration with the program's CSS project facilitator.
- Mental Health and Chronic Health Conditions
  - Continue the positive efforts made to increase the system's capacity in understanding that problems like anxiety and depression and trauma are the most common psychiatric conditions through CETs and other community trainings.
  - Consider adding some additional specific training opportunities that focus on how common GI issues are children and adults with IDD, and how these conditions (i.e. constipation and Gastro Esophageal Reflux Disease or GERD have been linked to irritability and aggression and may provoke a clinical picture that mimics an acute psychiatric event.

Emergency Service Trends

- Continue to provide outreach and other prevention services, to reduce emergency services use. while adding to the capacity of community partners to provide more proactive care in ways that promote physical and mental wellness for all individuals with IDD in the Region.

START Clinical Services

Primary Services:

- NH START has very low numbers of linkage agreements. It is recommended that the NH START leadership develop a plan of action to address this concern and set a target for completing additional linkages by the close of FY19. The diversity of current linkages should also be reviewed, and benchmarks set by the program, in consultation with the Center for START Services should be developed.
- Linkage agreement and relationship development should be focused on community stakeholders who interface with START regularly. These stakeholders might include community MH providers, area agencies, non-profits, primary care and psychiatric care management agencies and START advisory council members. While the execution of linkage agreements with hospitals is certainly important, the program should also

recognize the value in relationship development with a wide array of community service providers and stakeholders.

- Continue efforts to increase and track attendance at CETs, to expand the effects of this primary intervention tool, to increase system capacity in the care of people with IDD who have behavioral health needs.
- Develop a system for more closely tracking all primary services and identify all linkages, outreach occurrences, training topics and individuals attending any community (versus individually based) trainings.

Secondary Services

- The NH START team should develop an action plan to increase the percent of enrollees with an up to date START Plan, ABCs, and CSCPIPs and outreach services to be in line with national START fidelity standards by the second quarter of FY19.
- CSCPIP time tracking is lower than the percentage of completed and updated plans documented. This may be a data entry issue, or it could present an incorrect understanding of the crisis planning process. START CSCPIPs are organic, evolving documents, which are facilitated by the START coordinator with the full commitment and participation of the individual's team. It is important for the NH START leadership team to examine the reason for in-congruency and assure that clinical team members are engaging the system of support for enrollees.
- NH START should continue to collect regular data on outcomes associated with improved functioning and service effectiveness. As more components are being used, even greater reductions in psychopathology measured by the ABC would be an important indicator of the significance of these additions.

Tertiary Services

- Continue outreach efforts that increase collaborations and accessing of START crisis supports from community systems serving START enrollees.
- A plan needs to be developed in order to guide team leaders and coordinators in identifying those individuals who would benefit from an in person assessment, given the low rates reported for FY18.
- NH START team should review crisis disposition data and assure accuracy.

Therapeutic Supports

- Continue efforts to increase Resource Center utilization, especially for planned admissions. The NH leadership team should track this monthly and discuss strategies to ensure ongoing growth in this area.
- NH START must develop strategies and outline actions steps to assure that discharge summaries are completed and distributed in a timely manner. These summaries are an important tool that coordinators share and use to conduct outreach with individuals and their systems of care to promote positive outcomes.