Virginia START Quarterly Consult Summary
7/12-9/12

Following is a summary of progress in the development and implementation of statewide START services in the state of Virginia from July 1, 2012 through September 30, 2012.

The move forward in the development of VASTART allows for a validated model of service delivery to be used to establish effective community based services and supports for individuals 18 years and older with IDD and mental health needs. Progress this quarter includes an increase in referrals and services across the state. Early preliminary data will be presented to describe what we have learned so far. Careful attention to training, linkages and a qualified workforce along with evidence- informed practices are keys to the success of the project. Regions 3-5 have completed all needed trainings to date, while Regions 1 and 2 are rapidly catching up, since the hiring of needed staff has occurred more recently.

VA START Directors and Coordinators are preparing for certification and we have begun the process of reviewing needed materials. Regions 3 and 5 have made the most progress in this area. Regions 1 and 2 are still not licensed and thus cannot see clients so they will have to delay certification.

Implementation of VASTART Services Summary

Much progress has been made in the implementation of VA START services. It is important to note that Regions 1 and 2 are not yet licensed and therefore have provided no services. They are doing all they can to ready for licensing, and have hired and trained staff so that they can be up and running as soon as possible when licensure is obtained. Therefore, they do not have data to contribute to this report.

The Clinical professional support (MD and Ph.D.) for teams has been a challenge that we will work on together. Regions 3, 4, and 5 do not have psychiatric expertise as part of their teams. While Regions 1 and 2 have impressive support in this area. The lack of expertise in psychiatry in many locations may contribute to the lack of good diagnostic data and a high rate of hospital recidivism (as noted in the data). VA START will continue to work diligently to help fill this gap. In addition, the Region 1 VA START team has been unable to find a Psychologist/Clinical Director to date. Again, remedies will be sought to support their need for clinical expertise.

We continue to work toward the opening of regional VA START therapeutic respite programs. It is expected that two respite programs will be opening in the next quarter while two more will open early in 2013. The Region 5 respite program is not scheduled to open until the spring of 2013.

Clinical Education Teams will begin in the next quarter. All Clinical Directors have been participating in the Clinical Director's Study Group in preparation for this important forum. In addition teams continue to meet on an ongoing basis with their Advisory Councils made up of stakeholders in each region.

Following is a preliminary analysis of data reported in SIRS to date up until the end of this reporting period (9/30/12).

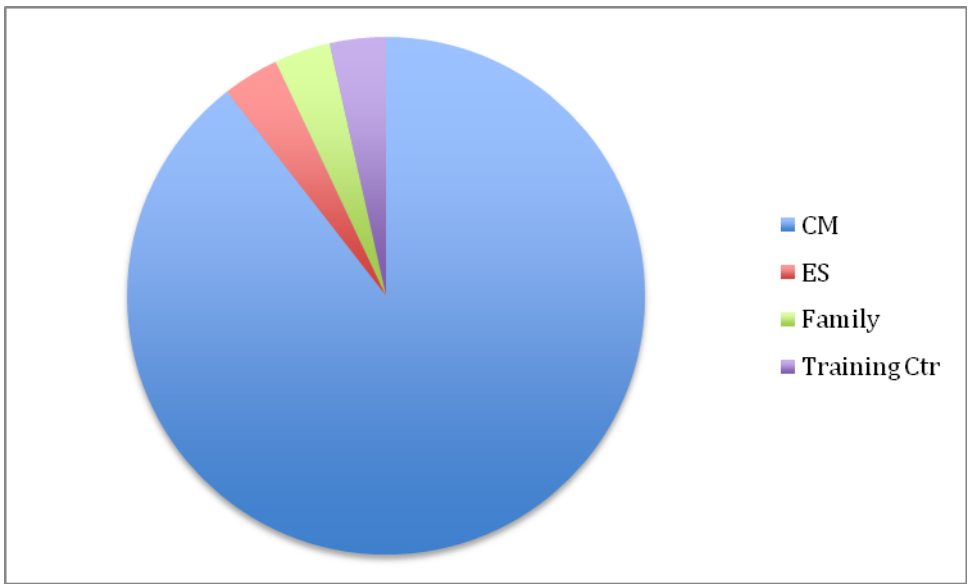
Background

Since Regions 1 and 2 have not provided services as yet, this report provides only preliminary aggregate data for Regions 3-5. To date 124 individuals have been entered into the START Information Reporting System (SIRS) data system and are receiving services through VA START. This number is not consistent with the numbers of referrals reported directly by each region. The database and staff are new so that problems will arise, but it is expected that there will be improvement in the next quarter with regard to reporting and data entry as we move forward in the process. In spite of the reporting limitations the data provides a starting place to assess the process, and given the brief time the program has been in place, there is much to report. The demand on the service to date (which is not yet completely operational), is impressive, and it should be expected that once the other two regions and respite programs have begun the numbers will increase dramatically.

Client Data

Following is data from referrals during the period that ended on September 30th, 2012. There were a total of 124 clients entered into the SIRS system between July 1 and September 30, 2012. It is noteworthy that Directors reported that not all individuals referred were entered into the system at the time of the review. The total number summarized in this report is 124: Region 3 = 40, Region 4 = 49, and Region 5 = 35.

Distribution of referral sources during the first quarter of FY2013.



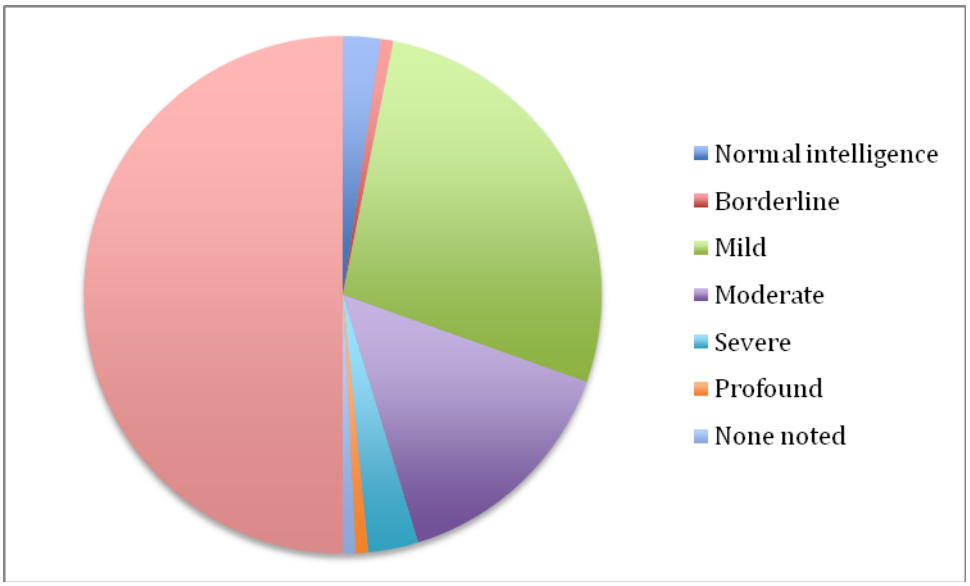
This table portrays the reported source of referrals in the SIRS. The data indicate that the vast majority of referrals came from case managers/care coordinators (91%). Training Centers referred 4%, Family members referred 3% of referrals reported, followed by day program (1%). While a small number of referrals were made by CSB emergency services (4%), this number along with the other referral sources are expected to increase significantly in the next quarter in locations where emergency respite programs will be opening.

We do not currently have the distribution of referrals. It will be important to monitor where people are located to insure access to all in need within and between regions over time.

Population information

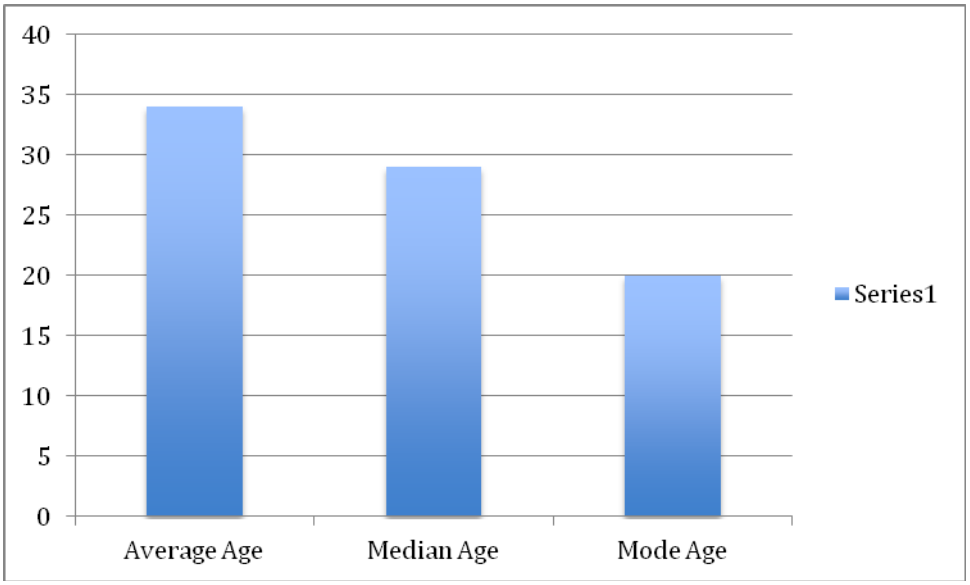
55% of all referrals were male, while 45% of referrals reported were female. Other population information reported includes level of intellectual disability, reported age, residence at time of referral, primary problem or reason for referral, and mental health diagnoses.

Frequency Distribution of Diagnosed Intellectual Disability



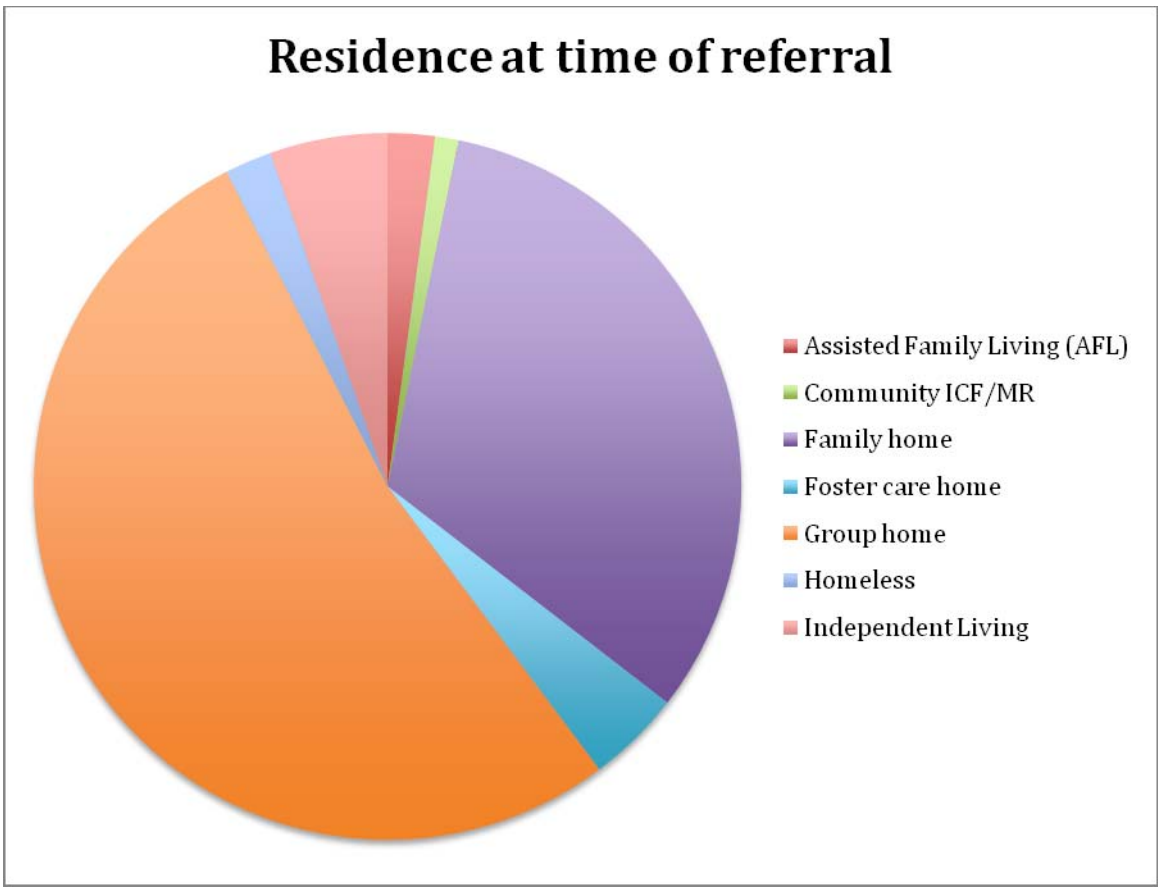
According to the data reported to date, as expected, the predominant number of persons referred have mild intellectual disability (59%), followed by moderate ID (31%), severe ID (4%) and profound ID (1%). In addition, 3% of individuals referred do not have a diagnosed intellectual disability. As would be expected, this population is more disabled than the general population of people with ID where 70% or greater would be expected to have Mild ID, and about 25% would be expected to have Moderate ID. This indicates that the population of individuals served by VA START is more vulnerable than the general population of individuals with Intellectual Disabilities.

Age distribution (n=124)



The age range of referrals was from 18-70. The mean or average age is 34; the mode or most common age reported was 20; and the median age was 29. This indicates a young adult population is the most prevalent so far, a finding found in other programs throughout the U.S.

The table below presents a frequency distribution of residence at the time of referral. This finding indicates that with regard to community housing, the VA START program is on target in supporting families at the earliest stages of development.

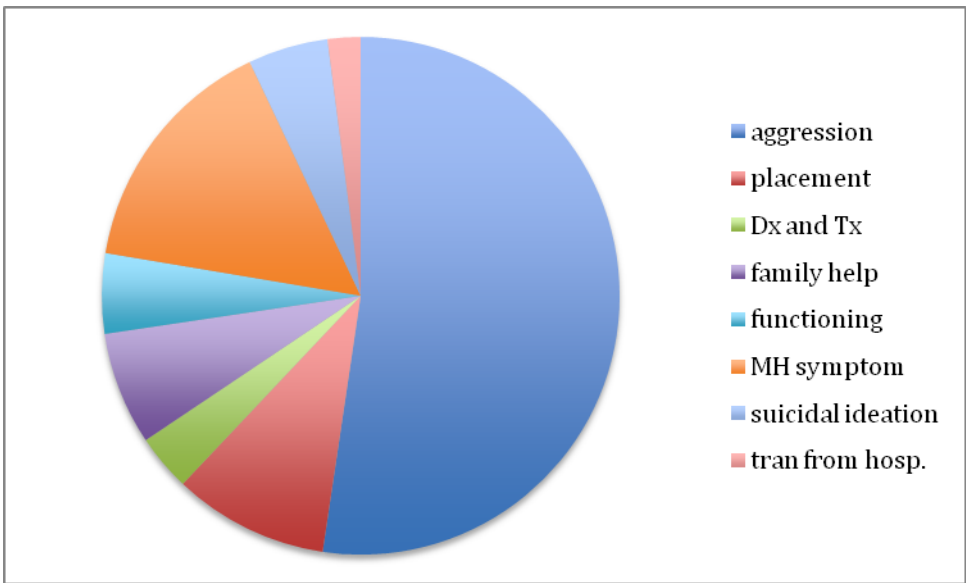


As expected, nearly half, or 49% of individuals referred resided in group homes at the time of referral. The distribution of referrals also indicates that 29% of all referrals are of people who lived with their families. An additional 4% lived with foster families. This means that 33% of referrals reside in family settings. This number is expected to rise to nearly half of the population over time once planned respite is in place, but a very good indication that the programs are well on their way to reaching an important target population. While Region 3 reported that 2 individuals resided in training centers at the time of referral, this was not included in the SIRS data at the time of this review.

Presenting Problems at Time of Referral

The average number of problems reported per referral was approximately 3. The majority of presenting problems at the time of referral were as expected due to some form of aggression (52%), followed by general mental health symptoms (20%). Other mental health symptoms reported included suicidal ideation (5%) and decreased ability to function (5%).

Presenting problems at Referral

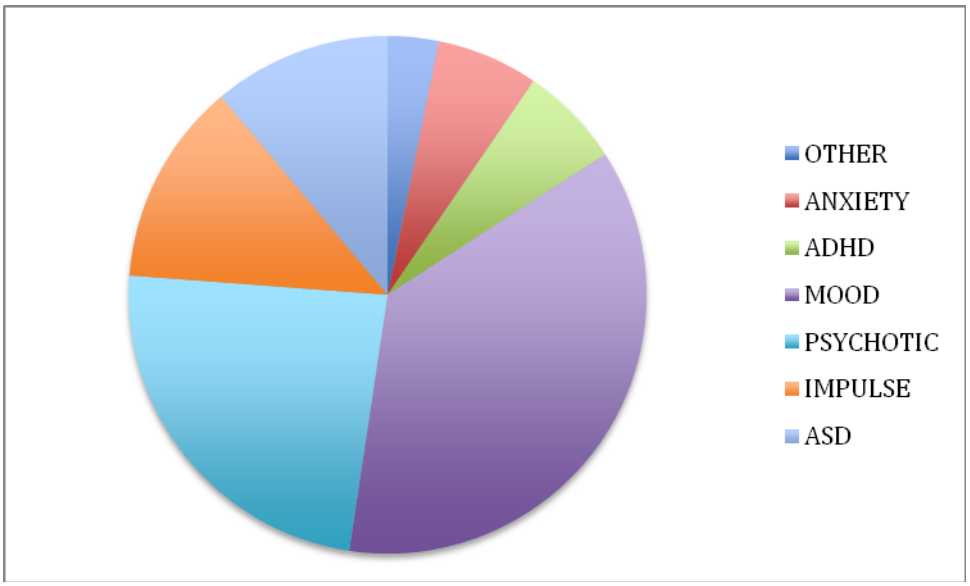


Presenting problems also included some service related problems. A number of individuals were identified as at-risk of losing placement (10%), need for family assistance (7%) the need for diagnostic and treatment assistance (4%), and transition from hospital (2%).

MH Diagnoses

It is important to note that this summary contains data that may have some difficulties to resolve. An example is the reported mental health diagnoses at the time of referral. The data indicates that while many have received mental health services including the majority who receive medications, only 44 of the 134 reported DSM IV-R diagnoses at the time of referral. There were a total number of 70 diagnoses reported for the 44 individuals. This finding may be indicative of reporting error combined with other factors that will be evaluated by the team and reported in the next quarter.

Mental Health Diagnoses reported at time of referral for 44 individuals (35% of population)

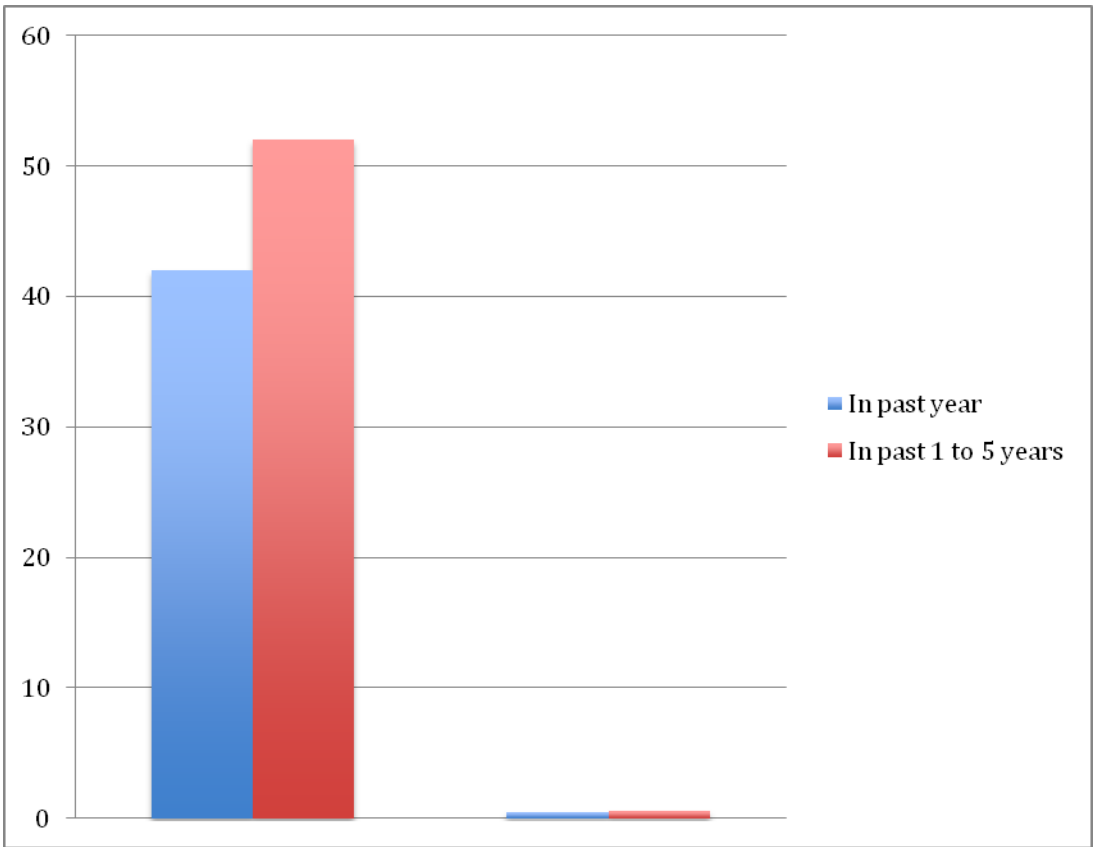


The vast majority (65%) had no reported mental health diagnoses in the SIRS as of September 30, 2012. Overall, the number of diagnoses in the SIRS is questionable, as we would expect a much higher prevalance. This chart only includes the distibution of diagnoses for 35% of the population of START referrals in this reporting period. In additon, the diagnoses reported are not reflective of what we know of the population. While it is not surprising that the majority of individuals were noted to have mood disorders (53%), anxiety disorders are usually very high in the population but are only reported in this sample 10% of the time. Psychotic disorders are higher than expected (34%), followed by Impulse Control Disorders (18%), and Autism Spectrum Disorder (16%). The total number of diagnoses was 70 so that 63% of the population had more than one prevalent disorder documented. This is a common finding.

The mental health diagnosis data may indicate the need for more education of treaters and greater expertise in serving indiviudals with IDD who have mental health needs. This is a goal of VA START and will be monitored closely over time.

In spite of the low number of mental health diagnoses recorded in the SIRS database for the indivuals referred to START to date, a high number have had psychaitric hosptializations according to the data reported.

People reported with prior hospitalizations (n=94)

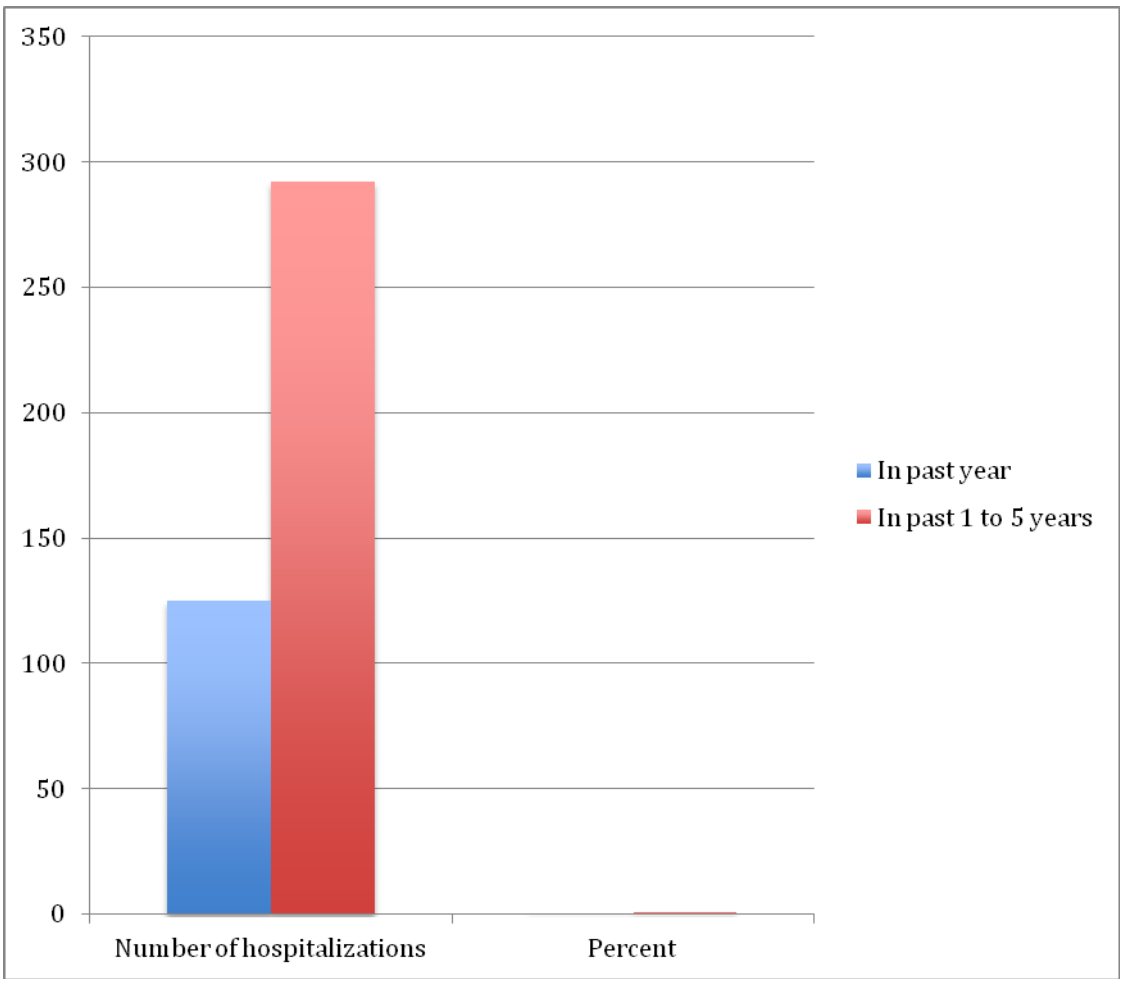


It was reported that 94 of the people referred or approximately 75% of referrals to date had previous history of psychiatric hospitalizations. Since this is the target population for referrals, this is not an unexpected finding. A goal of the VA START program is to enhance community capacity overall to reduce the need for hospitalization whenever possible.

Fifty five percent had at least one admission in the past five years (n=52); while forty five percent had an admission in the last year (n=42).

Following is the reported frequency of admissions over the same time period reported at the time of intake for VA START.

Frequency of reported number of prior hospitalizations at the time of referral for 94 individuals (n=417)



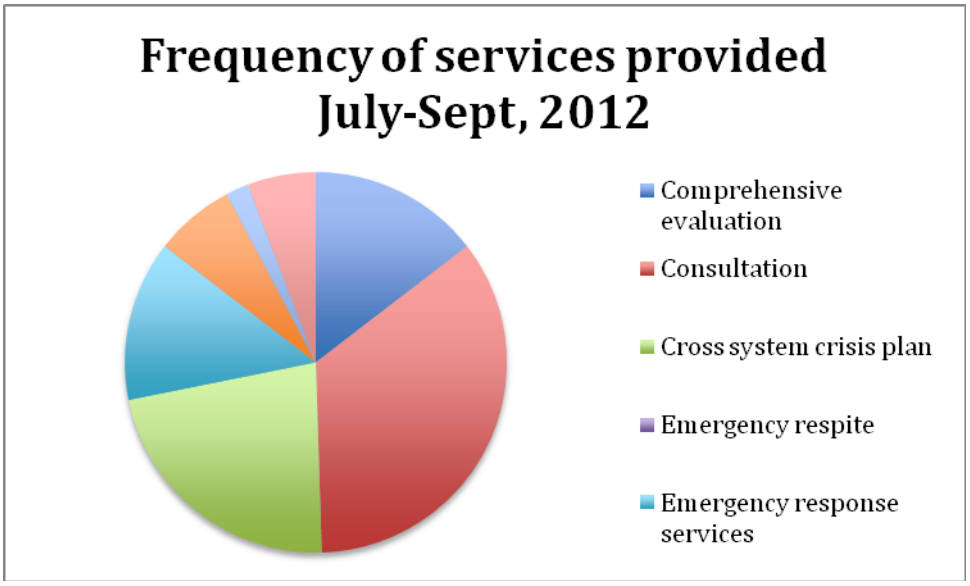
Of the 94 people who were hospitalized, it was reported that 30% of the admissions occurred in the last year with a total of 125 admissions, and over the past five years 70% of the population were hospitalized for a total of 292 admissions.

Forty-two people had a total of 125 admissions in the last year for an average of approximately 3 admissions per individual over the last year. In addition, 52 individuals were hospitalized over the last five years for an average of approximately 6 admissions per individual reported. This data indicates that these

people have high hospital recidivism rates. An important goal of the VA START program will be to address this issue and attempt to reduce the rate of repeated hospitalizations over time.

Total VASTART Services Reported as of 9/30/12

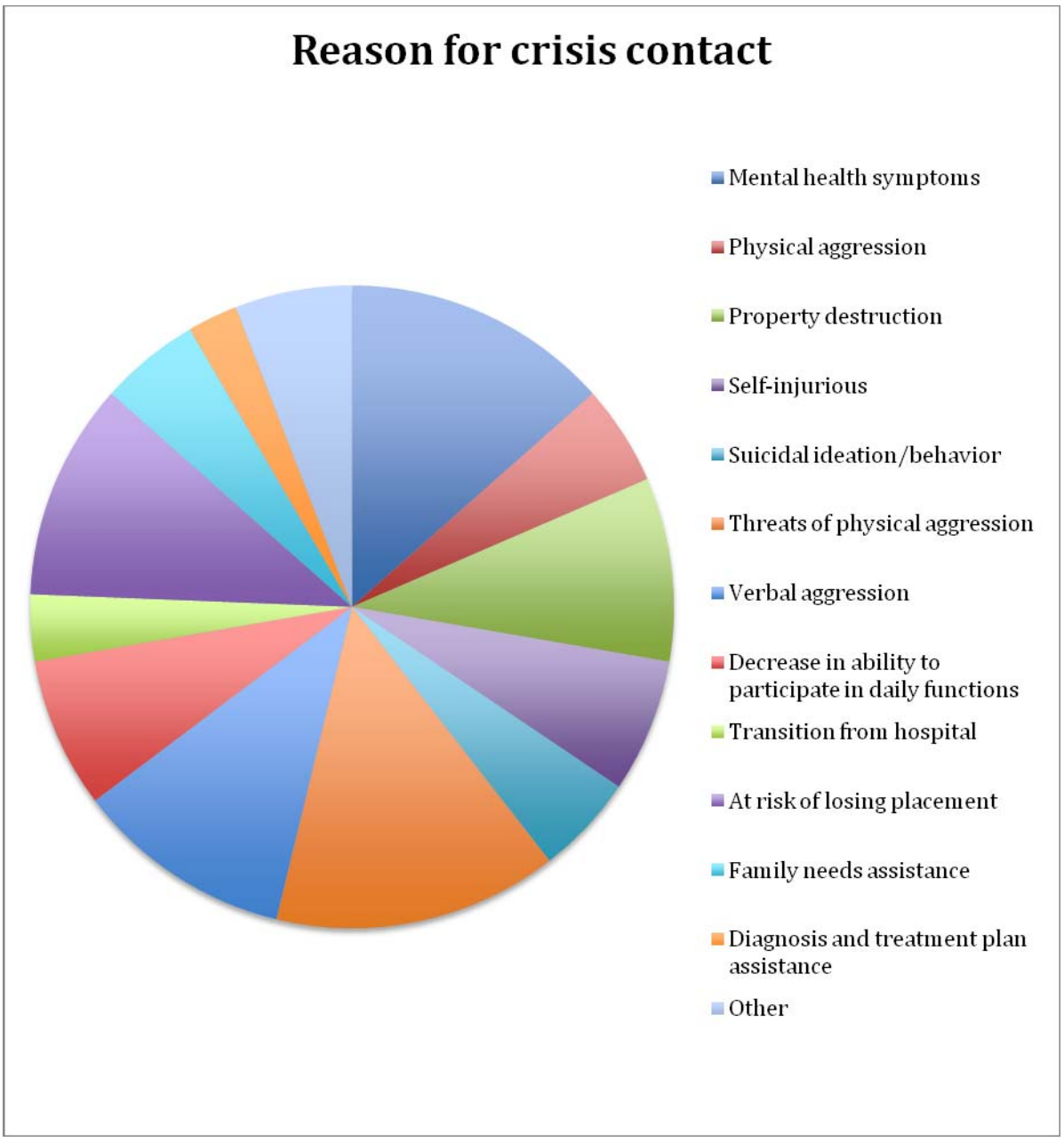
Following is the aggregate frequency distribution of services provided during the first quarter. No services were reported for regions 1 and 2 as noted earlier. In addition, only Region 3 provided in home respite services and no other respite services were provided during this period.



Of the 124 individuals referred, 104 received services this reporting period. A total of 109 services were provided. The majority of services were consultative supports (36%), followed by 22% Cross Systems Crisis Prevention and Intervention Planning, 15% VA START Comprehensive Service Evaluations, 14% emergency response supports, and 7 %of services to 7 individuals were reported to receive emergency in-home respite (Region 3 only).

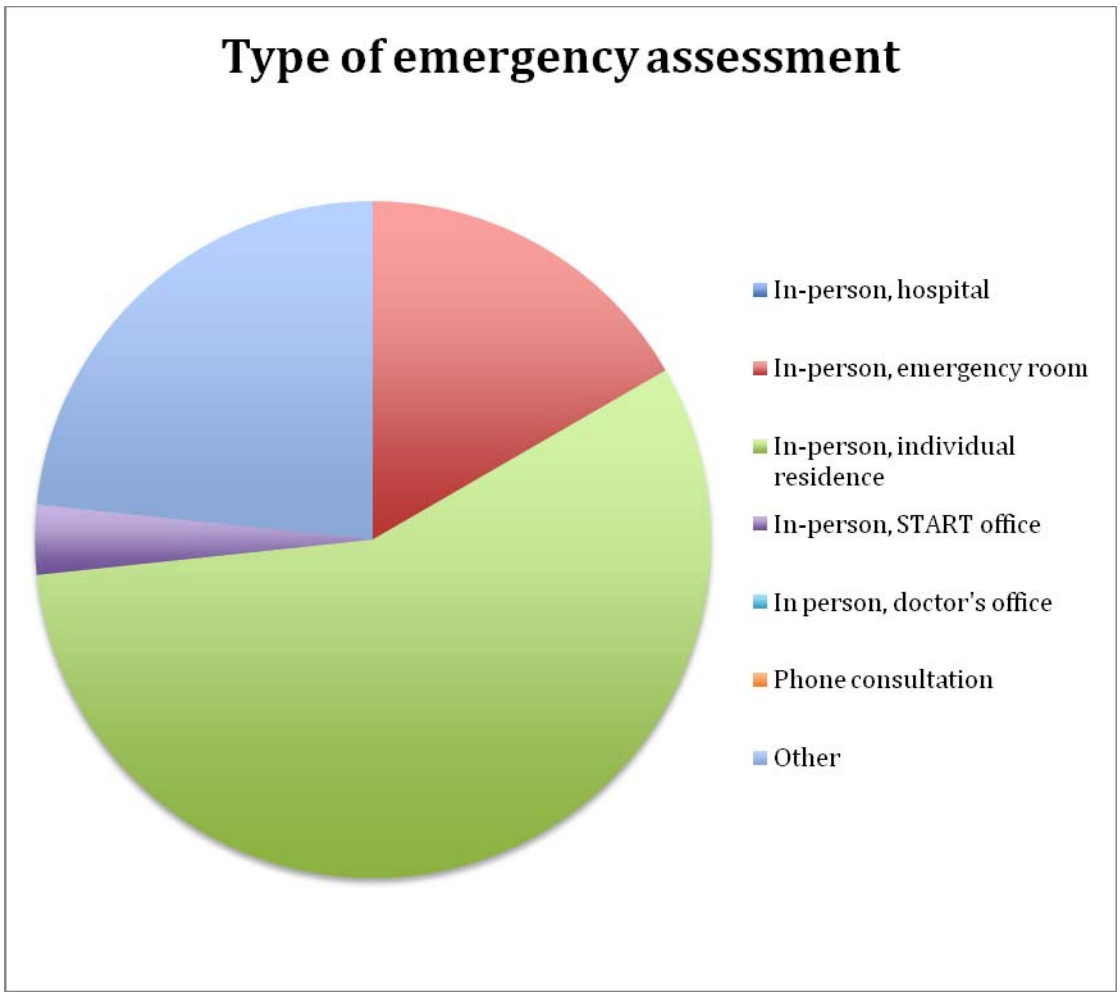
Emergency contacts

Regions 3-5 provided after-hours and emergency supports during the reporting period. Following is information entered into the SIRS with regard to the reasons for contact and dispositions that occurred following these emergency assessments.



This graph outlines the reasons for crisis contact this quarter. While the distribution appears to be somewhat mixed, the predominant reason for referral is due to some form of aggression either to others or self (40%), followed by acute mental health symptoms (13%), risk of losing current placement (11%), decrease in ability to function (8%), need for family assistance (5%), and diagnosis and treatment assistance (3%). It is impressive that while most people were referred for aggression, attention to functional levels, risk factors, and mental health symptoms also occurred. This indicates that VA START is on the right track in communicating that crisis prevention is a major goal of the program.

Following is the type of assessment conducted as part of the emergency contact.



The teams phased in emergency assessment over this time period so that the data is very preliminary. However, it is a positive outcome to date that 100% of the assessments were completed in person. Outreach is a key to VA START and since the population and programs are new, it is expected that all emergency assessments will be completed on site and not over the phone. This will change over time with improved knowledge of clients and the system, along with crisis prevention and intervention planning. The vast majority of assessments were conducted in the person's home (57%), while 17% were conducted in the hospital emergency room. In addition, 3% of assessments were conducted at a START office. It is interesting that 23% of emergency assessments were reported as conducted in locations other than those listed. More detailed accounts will be provided in future summaries.

Respite services

In-home respite was reported only for Region 3 in the first quarter. The predominant service provided was reported to be crisis prevention and intervention planning. A total of seven individuals were reported to receive in-home respite services.

UNH/IOD Services and Supports

In additon to this quarterly independent analysis, members of the UNH/IOD National START team visit at least one region per month to provide technical support, consultation and training services. In addition, we meet monthly with all Directors, provide a study group with Clinical Directors monthly, and meet monthly with each region via conference call to provide ongoing consultaiton and support. Monthly consultation summaries are sent to each region and Bob Villa for review following each visit. Consutlation notes are documeted by Regional Direcotrs following each telephonic meeting and shared as well. Crisis plans and Comprehensive Service Evaluations are also being reviewed and edited in preparation for the certification process to begin in the spring of 2013. In additon, training both in Virginia and via the web are provided. Along with the above-mentioned services, linkages to other START teams around the nation help to assist VA START whenever needed.

UNH/ Data Collection and Reporting

In order to provide an effective service delivery system and continue to assess progress in meeting our goals, VA START has worked in close collaboration with the University of New Hampshire to meet the specific data collection and analysis needs of VA START. The first phase of the data collection and reporting process for the SIRS was completed in FY12 with a pilot process conducted in Region III.

Revisions were made to the SIRS based on feedback from the VA START team members involved in the pilot and administrators. Four web-based training sessions for all VA START team members were conducted in late July/early August on use of the SIRS. User names and passwords were established for each VA START member. The SIRS was rolled out live for all to begin entering data on August 21, 2012 at www.sirsdata.org.

Utilizing VA determined unique ID numbers, the SIRS database now captures de-identified health information about individuals receiving START services and has the ability to provide reporting by case load, by region, and by state. Analysis of service outcomes will provide valuable information on service effectiveness over time and provide a management tool for decision-makers.

The required Business Associate Agreements (BAA) are now established with all regions.

In addition, we have continued to field questions and make adjustments to the data dictionary and access rules ensuring that those VA START members who need access in and/or between regions have it.

The development of standardized reporting formats has begun with the ability to summarize the data collected by caseload, region, and state. The reports also allow for the identification of trends in a variety of areas including service use and effectiveness of START services. The SIRS reports will also provide a capacity for VA START team members or administrators to download current data at any time to address internal needs/questions.

Training

Attached to this report are the training outlines for the clinical team and respite programs. All Regions have participated actively in all trainings. The focus in the coming months will be on respite staff since this service is expected to be fully operational by the end of the calendar year in most of the state.

Final Recommendations

VA-START service development is well underway with evidence-informed and evidence-based practices to improve community services to individuals with IDD and behavioral health needs. Much progress is being made.

Following are recommendations as we move forward with the process.

1. Provide the support needed for Regions 1 and 2 to begin to provide services as soon as possible.
2. There continues to be concerns expressed by Directors that the ability to collaborate with Emergency Services teams varies from location to location. This must be addressed along with clarification of the roles and responsibilities that continue to be in question.
3. The development of statewide resources means that those who have clinical expertise will be asked to share with those who do not. The Directors have been generous with their willingness for this to occur; it is just a matter of working on the details, which we will pursue, in the next quarter.
4. We need to develop clear protocols for the consultation process with the training centers, including criteria of who should be referred to VA START teams and when.
5. The SIRS database dictionary needs more detail and revision. I will meet with all Directors and Linda Bimbo to review SIRS during my visit to Region 5 in November 2012.

6. We need to explore obstacles to reporting accurate and complete data into the SIRS to insure that this occurs.
7. The reporting of outcomes must have the input of the Advisory Councils. As a result, it is important to give them the opportunity to review this report as part of the process prior to it going to the State as a final report. Therefore, the following process will occur:
   a) The data will be in by the last day of the end of the quarter.
   b) I will analyze and submit a DRAFT report to Directors within 30 days.
   c) The DRAFT report will be sent to Advisory Boards for review and comment.
   d) Comments will be sent back to me within one week by START Directors.
   e) The Final Report will be submitted to the state in its final version on or before the 15th of the month.

   This means that the next report will be submitted to the state of Virginia on or before February 15, 2013. This will allow for review and input of all stakeholders, an important part of the VA START program model. Monthly consultation notes, along with ongoing access to needed date upon request will be available as well.

   It is a great pleasure to be working with the Regional teams in the State of Virginia in the development and implementation of VA START. We have a great deal of work ahead of us, along with a talented group of professionals to achieve our goals. Congratulations to all for a job well done!

   Respectfully submitted,

   Joan B. Beasley, Ph.D.
   Director Center for START Services
   UNH/IOD