



A program of the Institute on Disability/UCED, University of New Hampshire

Long Island Service System Analysis

June 30, 2015

Executive Summary

Based on current census data, an estimated 400,000 (or 2% of the total population) of NYS citizens have Intellectual/developmental disabilities. New York state data indicate that 130,000 or 1/3 of those citizens with IDD, currently receive OPWDD services. Also according to NYS data, 37.5% (N=48,000) of the people in the OPWDD also have a psychiatric diagnosis. Based on international prevalence studies and consistent with the state's own experiences, it can be estimated that an additional 82,000 citizens with IDD, not currently in the OPWDD system may also have behavioral health care needs.

In collaboration with the New York State Office for People with Developmental Disabilities (OPWDD) and local stakeholders (including family members, self-advocates, and service providers), the National Center for START Services at the University of New Hampshire Institute on Disability conducted an analysis of the current service system in Nassau and Suffolk counties on Long Island (LI), OPWDD Region 5, for individuals with intellectual/ developmental disorders (IDD) and mental health needs. This was conducted in preparation for the planned implementation of NYSTART services in Region 5/LI in fiscal year 2017. While this report describes services needed on "Long Island," Long Island is defined by the make-up of Region 5, consisting of Nassau and Suffolk Counties. The remainder of LI region was included in the NYC analysis previously conducted.

The transition from institution-based services to community-based services in New York State requires the system as a whole to remove obstacles that segregate and isolate people with developmental disorders from access to effective care and treatment in their local communities. An important goal is to avoid the need for hospital emergency rooms and other crisis based services whenever possible. Many of individuals who currently reside in campus base settings have mental health and/or behavioral health needs. Furthermore, New York Medicaid claims data indicates that in 2013 and 2014, 4-5% of individuals (N=4700) known to OPWDD access emergency room services for psychiatric symptoms annually resulting in a total Medicaid cost of 3 million dollars. With the average cost of an emergency room visit estimated at \$2100.00 per person, the actual emergency room service cost for those that are known to the OPWDD system (n=4700) is estimated at 9.87 million dollars, which is significantly higher than the 3 million dollars that was billed to Medicaid for these services during this time period.

While State campus and Medicaid claims data provide important information, it is limited in scope, as it reflects sub-populations of service users. However, they may be indicative of a greater need for the community at large. Several thousand people across the state who receive OPWDD services have visited hospital emergency rooms for mental health assistance. This limited data review did not include an analysis of other costs associated with use of emergency rooms, the high cost of prescribed



A program of the Institute on Disability/UCED, University of New Hampshire

psychotropic and psychoactive medications or other OPWDD services such as multiple placements, enhanced staffing and other costs which are typically required when individuals with IDD have unmet mental health needs in the community.

In October 2014, OPWDD convened a multi-stakeholder group of participants and invited them to assist with the process of identifying and improving existing service supports for this population. The LI IDD/MH Task Force assisted with gathering information from across Long Island on the service needs of individuals with IDD accessing behavioral health services with the goal of developing the most effective approach to the START model based on the system's current makeup. The questions to be addressed in this analysis were:

- How effective is the current community system of care on Long Island in addressing the needs of individuals with intellectual/developmental disabilities and mental health needs/challenging behavior?
- How can the LI-NYSTART program help to enhance Region 5's existing service delivery system to improve services and supports to those in need?
- What should the program design of LI-NYSTART look like?

A multi-pronged approach was utilized to ensure that as many constituents as possible had an opportunity to contribute to the process and share their experiences.

Available statewide claims data was reviewed to assess targeted Medicaid expenditures. An evidence-informed web-based survey was made available across the city, 9 focus groups were held across constituency groups, and individual interviews were conducted with 26 family caregivers using a telephonic research-based survey. Finally, a Clinical Education Team (CET) training was held with a Region 5 provider to help begin the process of learning about case specific challenges and to inform the community about the START approach. Participants in the analysis represented a broad range of stakeholders and included self-advocates, families, service providers, and first responders. Over 1150 Region 5 citizens volunteered to participate in this process.

Based on claims data reported, over 109 million Medicaid dollars are spent annually for persons in the OPWDD system to address their mental health needs. While costs were reported for outpatient services, the data reported for outpatient services was aggregated so that we were unable to determine how many people used these services or what percentage of the population they represent. We can determine that 70% of mental health Medicaid expenditures reported were on outpatient services.

Over the course of 2013-2014, an average of 33 million dollars or 30% of expenditures was spent on emergency (3 million) and short-term, tertiary acute care services statewide (30 million). These services



A program of the Institute on Disability/UCED, University of New Hampshire

are limited in scope and effectiveness. Repeated emergency room visits indicate that remedies provided were not sustainable ones. While only a small percentage were hospitalized, 25% of expenditures overall were on inpatient services provided to 1% of the population. Inpatient stays were significantly longer and more costly than would be expected in the general population of mental health service users. This may help to explain the strain on the system described by mental health providers in this report. The high cost of emergency room services statewide is one important indication that there is a need to build capacity in the system of care as a whole to better serve people with IDD and behavioral health needs in the community.

Based on the data provided and the number of people who reside Nassau and Suffolk counties, an estimated \$12.5 million Medicaid dollars are spent in Region 5 each year for mental health services for this population. The feedback from stakeholders indicates the need for more comprehensive services and cross systems collaboration in the system as a whole. While respondents report significant differences in perspective depending on their cohort group, several common themes emerged across constituent groups and reporting methods, including those that described direct and recent experiences.

Both the OPWDD and the mental health providers on Long Island expressed a commitment to improved collaboration and a willingness to work together on solutions. The primary concerns reported were: the need for greater crisis supports; improved training for providers across systems; better access to inpatient and outpatient mental health services; and more comprehensive IDD services to improve overall quality of life.

Conclusions:

The proper implementation of the START model can help to overcome many of the issues identified in this report. All NYSTART programs will have consistent services across the state. Recommendations from the piloted programs now underway in Regions 1 and 3, along with the NYC START review, will be incorporated into the LI-NYSTART program development. While some of the recommendations below are unique to LI's contribution, some are also a result from the previous NYC systems analysis.

1. Attention mental health and well-being, including meaningful life experiences and engagement is essential in addition to better treatment and support for those with mental illness and/or in crisis.
2. Active engagement with families and service users to ensure program effectiveness will be key to the program's success. Family/ self- advocate advisory boards should be developed for each region to assist in the implementation and improvement of START services across the state. This should not replace the stakeholder advisory board.



A program of the Institute on Disability/UCED, University of New Hampshire

3. In home supports and family caregiver coaching will be key elements of the LI-NYSTART program as well as other programs across the state.
4. LI-NYSTART should focus on high-risk transitional youth in a timely fashion and conduct a Comprehensive Service Evaluation (CSE) at least two years prior to transition to the adult system to assist in the appropriate development and implementation of services and supports in the adult system.
5. The LI-NYSTART program should establish operational, cross systems networks throughout the region through their regional teams. These networks will help to:
 - a) improve access to needed services and supports;
 - b) ensure services are appropriate and match services needed; and
 - c) foster accountability in the system as a whole to collaborate and improve overall life experiences, services and treatment to the population
6. Training across the system is needed to improve capacity in the community. This will require engagement of mental health partners to ensure meaningful training opportunities take place.
7. Crisis intervention services must occur early on and with the input of caregivers and service recipients to ensure their effectiveness. Reduction of emergency room use and emergency services overall should be a focus of all of the NYSTART programs.
8. Improved caregiver knowledge about specific services, including better communication about how to access existing services across systems.
9. Attention to the individual's life context, with strength- based supports is needed.
10. Continuous methods to provide and receive feedback should be established. Data collection and analysis will ensure that evidence informed practices are being employed and are effective.

Next steps/Recommendations:

While the START model appears to match the reported needs in the system, the emphasis early on must be on engagement of the entire system to operate the program effectively. Following are steps to effective program development based on the needs reported on LI:

1. Finalize the design of the LI-NYSTART programs (specific recommendations are in the end of this report). In the request for proposals to provide LI-NYSTART services, emphasis should be placed on the fact that START is an integrated behavioral health team that promotes strength based, person centered supports and services.



A program of the Institute on Disability/UCED, University of New Hampshire

2. Focus on positive mental health and wellness approaches will be key for the successful provider of this program.
3. The development of a plan by the LI-NYSTART team bidder to implement regional support networks will be key. The Center for START Services will work closely with the Regional Teams and other stakeholders to help with the establishment of START networks across Nassau and Suffolk Counties; however, existing relationships will be important to begin the process.
4. Development and implementation of the interdisciplinary professional learning community across LI and linked with other NYSTART programs must include technological support to foster access to training and consultation opportunities. The learning community should include family and direct support provider education and mentoring. The national START team will provide the needed training and consultation resources, including CME and CEU eligible study groups. Providers submitting proposals should have a plan to make these as accessible to as many stakeholders as possible.
5. LI-NYSTART programs must work closely and collaboratively with all first responders already established on Nassau and Suffolk Counties to ensure effective crisis response. Roles and responsibilities must be clearly established and defined as part of this process and joint trainings will be needed. Providers submitting proposals should address this issue.
6. LI-NYSTART programs should link with NYC multi-modal consultation teams in development to assist with assessment of individuals with more complex needs.
7. LI-NYSTART teams should attend established mental health and IDD provider meetings for a minimum of the beginning 18 months of development and operation to provide information and hear concerns. Providers submitting proposals should provide a plan to assure this occurs.
8. It is imperative that a review of inpatient mental health services occurs, including how to access and use them effectively. LI-NYSTART teams should be oriented to and linked with all inpatient services in order to have a clear understanding of what can be provided on the unit. At the onset, LI-NYSTART programs should establish that they will be there within the first 24 hours or the next business day to assist with discharge and treatment planning, support on the unit and ensure timely discharge from inpatient stays. Providers submitting proposals should include their plan for ensuring this occurs.
9. The LI-NYSTART teams need to develop a plan as to how they will interface with the education system and local schools. The proposed provider should have a plan to make this happen.
10. Data collection and analysis will be key. Proper equipment, ability to collect and report data including participation in the SIRS (START, Information, Reporting, System) will be needed.



A program of the Institute on Disability/UCED, University of New Hampshire

11. Stakeholder and family advisory councils should be formed. The proposed provider should have a plan to assure that this occurs.

It is suggested that these recommendations be incorporated in the request for proposal to ensure they are part of the program design.

Joan B. Beasley, Ph.D., Director

Ann Klein, MA, START Information Reporting Systems (SIRS) Manager

Andrea P. Caoili, LCSW, Director of Quality Assurance

University of New Hampshire, Institute on Disability UCED

Center for START Services



A program of the Institute on Disability/UCED, University of New Hampshire

Analysis of the Long Island Community System of Care for Persons with Intellectual/Developmental Disabilities and Mental Health Needs.

Introduction

The mission of NYSTART is to increase the community capacity to provide an integrated response to people with intellectual/developmental disabilities and behavioral health needs, as well as their families and those who provide support. This occurs through cross systems relationships, training, education, and crisis prevention and response in order to enhance opportunities for healthy, successful and richer lives. NYSTART programs are currently being piloted in Regions 1 and 3, with the expectation that it will be implemented in the Long Island (LI) region shortly after NYC, in late fiscal year 2016. For the purposes of this report, Long Island is the scope of OPWDD Region 5 consisting of Suffolk and Nassau counties. In addition to what is being learned from the pilot, direct feedback from local stakeholders about the existing system and needed supports is essential to this important initiative. The following is an analysis of findings through structured interviews, focus groups and on-line surveys, as well as a clinical education team forum conducted in partnership between The National Center for START Services and local providers. A list of participants and tools utilized in the analysis are provided in the addendum of this report. We want to thank all who participated.

Background

Across the United States approximately 1.5% to 2.5% of the population has an intellectual developmental disorder (IDD) (1). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM5) defines IDD as a disability that involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks. Epidemiological studies have established that the incidence and prevalence of mental health conditions for people with IDD is typically 2 to 3 times that of the general population (2) and that these mental health conditions often contribute to challenging behavior. For people with IDD, aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services (3).

Current NYS census data estimates that 400,000 (or 2% of the state's population) are diagnosed with IDD. 130,000 individuals (an estimated 1/3 of the population) currently receive OPWDD services, of which 37.5% (N=48,000) have a psychiatric diagnosis. Based on prevalence studies, and consistent with the state's own experiences, it can be estimated that an additional 82,000 citizens with IDD may also have behavioral health care needs.



A program of the Institute on Disability/UCED, University of New Hampshire

In New York State, over \$79 million dollars is spent annually to pay for a combination of out-patient community based mental health services (about \$76 million) and emergency room visits (about \$3 million) for this population. This does not include money spent on prescribed psychotropic medication. Best practice in supporting people with IDD and mental health needs requires system linkages to provide strategic outreach, education and consultation in order to reduce the frequency of emergency service use. In 2012, NYS OPWDD began the development of a strategic plan to improve access to community resources and improve the quality of life for people with IDD and co-occurring mental health conditions. They researched multiple program models and based on the needs of individuals living in New York State, and selected START as a good fit to meet their mission.

In New York state, there are approximately 130,000 individuals receiving services through NYS OPWDD and about 11.5% (N=15,000) of these individuals reside in Nassau/Suffolk counties of Long Island (Region 5). In order to better inform the implementation of START services, OPWDD requested a comprehensive assessment of the current system of care in Region 5 (Long Island). The goals of this analysis were to learn about what is working in the Long Island Region 5 system as well as to facilitate dialogue and discussion amongst stakeholders on the gaps in the system and how these can be improved through the implementation of START services.

The START (Systemic, Therapeutic, Assessment, Resources and Treatment) program, first developed in 1989, is designed to improve the care of individuals with IDD through the combined effects of a well-trained work force, utilizing a multidisciplinary and coordinated approach to assist individuals with IDD and behavioral health needs. Using what has been coined as a systems linkage approach, the core philosophy of the program is that there must be an emphasis on solution focused and active communication and decision-making in the system of care, in addition to a better understanding of individual, clinical and treatment needs to improve service outcomes.

Community based IDD Services are designed to promote a maximum quality of life and independence for people with these conditions. Services include residential, vocational, case management, family support and other person centered services. They also include positive behavior support planning for those who need it. They do not provide community based primary medical, neurological, dental, psychiatry or other medical services. These services are voluntary, are accessed as needed in the community and are provided throughout the lifespan.

Community based behavioral health services are considered episodic but can be provided long term when needed, and include, but are not limited to: prevention programs, outpatient therapy, psychiatric services, emergency and crisis intervention services. While most services are voluntary, some inpatient care is involuntary when needed. Emerging practices in the general population for evidence-based care requires close attention to and integration of mental health practices with primary medical, social and rehabilitative services in the treatment of mental disorders.



A program of the Institute on Disability/UCED, University of New Hampshire

While mental health services are used by individuals with IDD, prior NY based analyses and reports indicate that the use of these services for some was not consistently well integrated into a comprehensive behavioral health approach, and that the multiple systems providing care and treatment were not always clear in identifying roles and responsibilities in assessing and treating these individuals.

The overarching evidence from published research in this area is that there are a number of contributors to challenging behavior including environmental factors, medical conditions/discomfort, communication problems and psychological vulnerabilities as well as psychiatric conditions. Many of these issues co-occur for mental health service users whether they have IDD or not. Studies indicate the prevalence of psychiatric conditions in people with IDD is more than 25%. Effective behavioral health care requires an integrated approach to address all of these conditions. The goal of LI-NYSTART is therefore to help establish a network of community-based providers for an integrated behavioral health system of support to individuals with IDD that includes mental health services as needed.

Methods of Analysis

There were three overarching questions in the process. Citizens were asked to assess:

1. How effective is the current community system of care on Long Island in addressing the needs of individuals with intellectual/developmental disabilities and mental illness/challenging behavior?
2. How can the LI-NYSTART program help to enhance the existing service delivery system to improve services and supports to those in need?
3. What should the program design of LI-NYSTART look like?

Five methods were employed to gather information about the existing service system and to create opportunities for constituents to provide feedback about how to address issues. The methods were: a review of mental health expenditures for this population, focus groups, an online survey, telephonic family caregiver interviews and a clinical education team meeting.

Methods were reviewed with the task force and the online survey was modified as needed with their input (see tools used in Appendix A). The LI IDD/MH Task Force (see Appendix B) played a key role in distributing the survey across Long island as well as collecting the contact information for citizens who volunteered to participate in this analysis.

Method 1. Claims Data Review

The OPWDD Data Analysis Unit provided a summary of Medicaid mental health expenditures for individuals receiving OPWDD services in fiscal years 2013 and 2014.



A program of the Institute on Disability/UCED, University of New Hampshire

The estimated number of individuals served in NY State by OPWDD is 130,000. Of those individuals about 11.5% (N=15,000) reside in Region 5 (LI).

The table below provides the statewide Medicaid claims data for FY13 and 14 for individuals in the OPWDD system. This does not include those who do not yet have access to this service system but may be eligible. For each year, Medicaid expenditures for psychiatric/behavioral health outpatient services totaled over \$76 million dollars annually (Table 1) and \$3 million annually in emergency department visits (Table 2) for a total of over \$79 million in outpatient costs.

Table 1: Outpatient Service Costs

Outpatient Services	FY13	FY14
Regular Clinic Visits (DOH, OMH, OPWDD Certified Clinics - Hospital OPD and FS Clinics)	\$54,691,893	\$55,305,475
Practitioner Services	\$2,419,698	\$2,506,798
OMH Specialty Outpatient Services	\$19,492,856	\$18,315,062
Total Outpatient	\$76,604,446	\$76,127,336

In addition to outpatient costs, during 2013 and 2014, approximately 4-5% of the OPWDD population (over 4700 individuals) experience an emergency room visit associated with a mental health crisis each year at a cost of about \$3 million annually. This number includes only individuals eligible for OPWDD services with Medicaid, so the actual number of individuals with IDD using the emergency room for a mental health crisis is likely higher. The number of visits also suggests that many of those individuals experienced multiple emergency department visits during the year (Table 2).

Table 2: Emergency Room Costs

Service	FY13			FY14		
	Clients	Visits	Payments	Clients	Visits	Payments
Emergency Room Visits						
General Hosp ER Visit w/ Psych Dx	3,099	6,331	\$721,960	3,082	6,083	\$643,651
CPEP (Comprehensive Psychiatric Emergency Program)	1,589	3,095	\$2,472,449	1,641	3,572	\$2,847,631

Inpatient data

Table 3 presents the inpatient data provided for this review. Inpatient psychiatric admissions include general hospital psychiatric admissions and admissions to Institutions of Mental Disease (IMD)(State operated psychiatric centers, residential treatment facilities and private psychiatric hospitals). The IMD



A program of the Institute on Disability/UCED, University of New Hampshire category only includes Medicaid expenditures for children and seniors since Medicaid does not reimburse IMD expenditures for individuals between the ages of 22 and 64.

Inpatient psychiatric admissions were utilized for approximately 1% of people accessing OPWDD services at a cost of approximately \$29 million per year. The average cost per person was approximately \$21,000 each year (Table 3).

The number of individuals who have had inpatient admissions is small, but the resources spent on these services represents a significant percentage of Medicaid dollars spent on the population overall. During the two year period, the cost per inpatient admission per person was an average of \$21,000 and the length of stay for these admissions was approximately 25 days. This is more than twice as long as would be expected for inpatient stays in the general population of mental health service users.

Table 3: In-Patient Psychiatric Costs

Service Description	FY13			FY14		
	Clients	Paid Days	Payments	Clients	Paid Days	Payments
General Hospital-Psychiatric Admissions	1266	28736	\$25,112,512.36	1250	25750	\$22,629,416.45
Total IMD (Institutions of Mental Disease) Admissions	150	8273	\$6,263,481.22	128	5975	\$5,446,713.02
Total In-Patient Psychiatric Medicaid Expenditures	1416	37009	\$31,375,993.58	1378	31725	\$28,076,129.47
Average Length of Stay	26 Days			23 Days		
Average Cost per Person	\$22,158.19			\$20,374.55		

Implications of findings

Based on claims data reported, approximately 109 million Medicaid dollars are spent annually for persons in the OPWDD system to address their mental health needs. While costs were reported for outpatient services, the data reported for outpatient services was aggregated so that we were unable to determine how many people used these services or what percentage of the population they represent. We can determine that 70% of mental health Medicaid expenditures reported were on outpatient services.

An average of 33 million or 30% of expenditures per year over the two- year period was on emergency (3 million) and short-term, tertiary acute care services (30 million) statewide. These services are limited in scope and effectiveness and should only be used as a last resort. Repeated emergency room visits indicate that ER visits did not consistently provide sustainable remedies. While only a few were



A program of the Institute on Disability/UCED, University of New Hampshire

hospitalized, 25% of expenditures overall were spent on inpatient services provided to 1% of the population. Inpatient stays were significantly longer and more costly than would be expected in the general population of mental health service users. This may help to explain the reported strain on the system reported by mental health providers described later in this report.

Region 5 represents 11.5% of the of the statewide OPWDD population. Improvements in services and outcomes on LI can have a significant financial impact statewide. Based on the data provided and the number of people who reside in Region 5, **an estimated \$12.5 million Medicaid dollars are spent in Nassau/Suffolk counties of LI each year for mental health services for this population. Despite these expenditures, participants in this analysis indicate that services may not be as effective as they should be.**

The analysis of Medicaid claims does not include the social costs associated with use of emergency rooms, the cost of prescribed psychotropic and psychoactive medications or other OPWDD services such as multiple placements, enhanced staffing and other costs which are typically required when individuals with IDD have unmet mental health needs in the community.

Method 2. Focus Groups

The Center for START Services conducted nine focus groups across Long island with a variety of constituents. Each focus group represented a specific type of constituency including: self-advocates (people who use services); family members (2); mental health service providers (outpatient and residential); hospitals; IDD providers (outpatient and residential); and crisis service providers (see Appendix C for a complete list of groups). The purpose of these focus groups was to provide valuable, qualitative input in the overall process from the perspective of the people they represent.

Each focus group began with a brief overview of the START model followed by small group discussions that centered around two primary questions: “How well is the current system meeting the needs of individuals with IDD who need mental health services?” and “What advice would you give to LI-NYSTART program planners regarding the mental health service needs of persons with IDD and their families?” Each group was facilitated in-person by a National Center for START Services staff member. There was also a Center for START Services staff member participating telephonically to document the discussions taking place. All discussion documentation was coded using qualitative data analysis software (5) so that prevailing trends could be identified.

This review led to the identification of themes that could be compared with the data from both the online survey and the family interviews. In addition, on-line information and presentations about the planning and implementation of LI-NYSTART occurred in several forums over a twelve-month period prior to these sessions.



A program of the Institute on Disability/UCED, University of New Hampshire

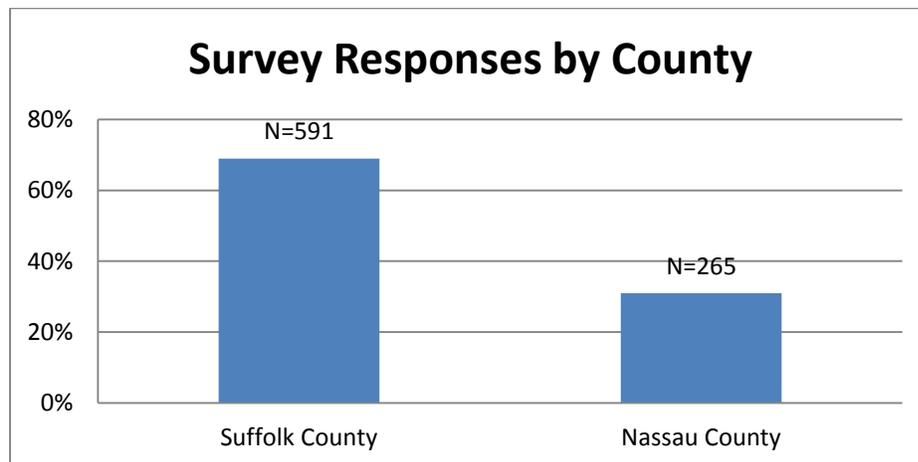
Method 3. Online Survey

A Region 5/LI IDD/MH task force was assembled to review, help to revise, and distribute the electronic survey link to constituents across the region including, but not limited to: IDD providers, mental health providers, family members, policy makers, medical and court staff, self-advocates, and special education personnel. In addition to emailing the link to individuals, a link to the survey was put on several state agency websites and social media. The goal of this effort was to receive feedback from as many people across Region 5/LI as possible.

In examining overall mental health service experiences for individuals with IDD on Long Island, the analysis focused on three primary areas that must be aligned to provide effective services: Access (timeliness, location, ability to use), appropriateness (services that match needs/wants, expertise is available), and accountability (individuals are satisfied with the services, and they find them helpful) (6). People who completed the survey were asked to consider each of these three criteria as it relates to a variety of mental health services.

A total of 955 Region 5/LI citizens responded to the survey between December 2014 and February 2015. The response was much higher in Suffolk County (69%) compared with Nassau County (31%). Figure 1 shows the number of individuals from each county who responded to the on-line survey. Not all respondents indicated a location.

Figure 1: Online Survey Responses by County



The representative distribution response rate for the on-line survey in Region 5/LI was across all cohort groups. The majority (57.5%) (N=550) of people who participated in the online survey were IDD and Mental Health Service Providers. IDD providers made up approximately 68% of this group, while mental health providers made up the remaining 32%. The providers reported significant experience in the field



A program of the Institute on Disability/UCED, University of New Hampshire

with an average of just over 16 years of service. This suggests that the individuals responding have significant knowledge of the current service system on Long Island. 21% (N=201) of the people who completed the online survey are family members and 2% are individuals who use the service system. 15.5% (N=148) of persons responding to the survey listed as “other” report very diverse roles within the service system including educators, advocates and medical personnel. The high response rate and the diversity of respondents suggest that citizens on LI are highly invested in this process and anxious to give input into the development of LI-NYSTART.

Figure 2 shows the percentages of stakeholder groups responding to the survey.

Figure 2: Online Survey Respondent

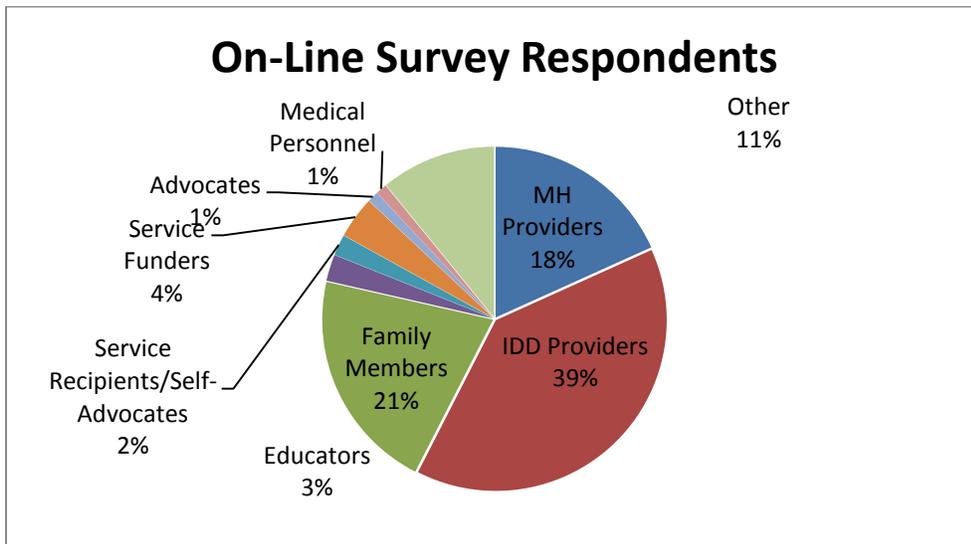
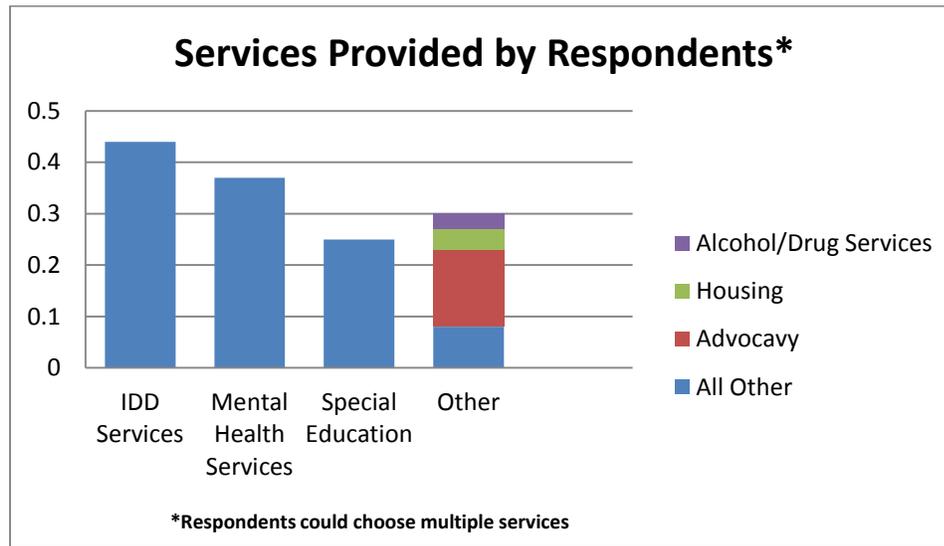


Figure 3 shows the types of services provided by people who responded to the online survey. For individuals who chose “other,” a breakdown of the most common responses is included. The remainder of services included in this category is medical, legal, child protection and recreational services. Providers who responded to the survey reported their service recipients include individuals across all age ranges in a fairly even distribution.



A program of the Institute on Disability/UCED, University of New Hampshire

Figure 3: Type of Services Provided



Method 4. Family Caregiver Experience Interviews

While the focus groups and online survey portray perceptions about the service system from a large number of stakeholders, it is important to consider the opinions of families who have direct and recent experiences using mental health services for their family member with IDD. The Family Experiences Interview Schedule (FEIS) developed by Tessler and Gamache (1995) (7) was used to gather information from 26 family members who had recent experiences (within the last year) with mental health services for their family member with IDD. The surveys sought family member feedback in three primary areas:

- (1) Relationships between family caregivers and professionals;
- (2) Family caregivers’ impressions of service effectiveness; and
- (3) Experiences of family members with the system.

In addition, family members were asked to assess whether their family member with IDD experienced unmet service needs, and, in two open ended questions, they were asked to give advice to service planners to consider.

Family member responses correlate with the overall findings of needs and trends from the broader community on-line survey and focus groups.



A program of the Institute on Disability/UCED, University of New Hampshire

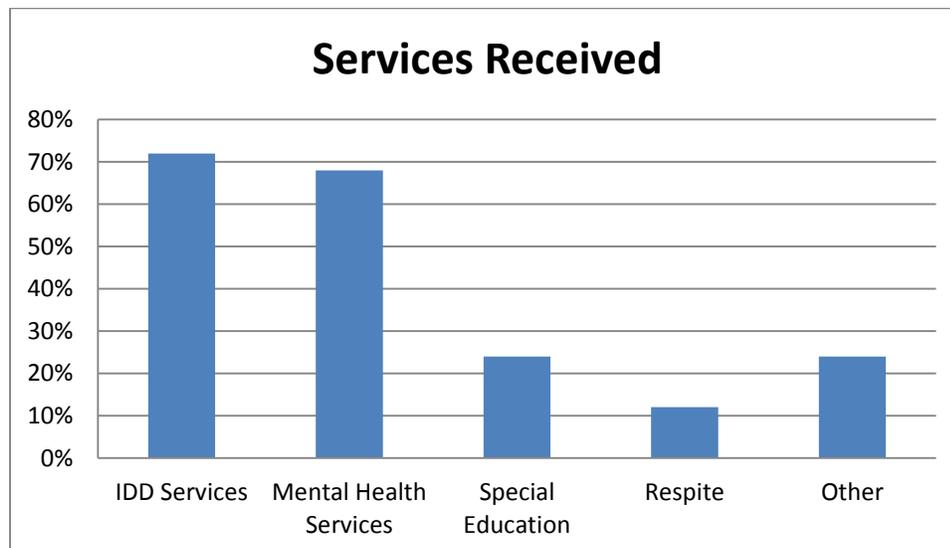
Description of Family Member Phone Interview Respondents

Survey respondents were recruited from across Region 5/LI with the assistance of advocacy organizations, family support networks and provider organizations. Twenty five of the survey recipients are parents and one is a sibling of an individual with IDD; with 88% of respondents being female with an average age of 59 years old. The majority of respondents (77%) report having some college education and 54% were working either full or part-time at the time of the survey. 45% report a family income of at least \$100,000 annually. 58% report that they consider their own health to be good and 15% report their own health as excellent. **More than three quarters of respondents (77%) report that it has been somewhat or very difficult caring for their family member throughout the past year.**

Survey recipients were asked to share non-identifying demographic information regarding their family member with IDD. In 77% of the interviews conducted, the family member with IDD is male with an average age of 27 years old. This finding is consistent with trends of adult populations who receive START Services across the country. According to the START Information Reporting System (SIRS), which is the national START database, the majority of referrals for START Services are for young adult males.

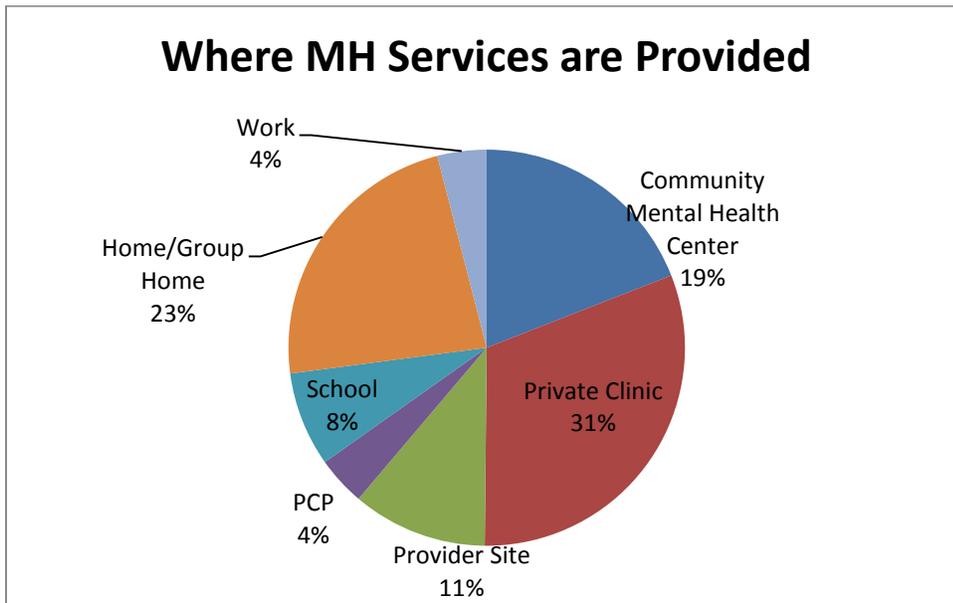
Figure 4 shows the distribution of the services currently received by survey recipients and their family members. While 68% of the individuals are currently receiving mental health services, there is a wide variation in the locations where these services were being provided, as seen in Figure 5.

Figure 4: Types of Services Received



A program of the Institute on Disability/UCED, University of New Hampshire

Figure 5: Settings Where Services are Provided



Method 5. Clinical Education Team Demonstrations

A Clinical Education Team (CET) demonstration was presented with a Long Island provider agency on May 20, 2015. CETs are forums designed to improve the capacity of the local community to provide supports to individuals with IDD and behavioral health needs through discussion of a case. The training is not only about the person presented, but rather descriptions of the problems faced, strengths and resources, as well as diagnosis and treatment information so that the individual serves as an example for discussion and further examination. It is also expected that the discussion will generate ideas about possible remedies to explore to improve services and clinical outcomes for the individual presented. The Region 5/LI CET was well prepared and attended by stakeholders. It reflected an interest in improving services and the need for more comprehensive service evaluations and diagnostic assessments. There was also representation from at least one Region 5/LI provider at most of the other CETs that were held in New York City.

Integrated Analysis of Findings

Following is an analysis of findings that incorporate all methods of data collection.

The three primary cohort groups that participated in this systems analysis have differing perspective as to how to improve service effectiveness. While Mental Health providers report gaps in the IDD system as contributing to stress in the mental health system, the IDD system providers identify lack of collaboration and poor access to mental health services as a major obstacle in the community system.



A program of the Institute on Disability/UCED, University of New Hampshire

The least satisfied respondents are families and service users who report a lack of services and supports with expertise across all system areas.

“Parents seeking acute care for children with mental health and dual diagnosis find few to no options, resulting in a lack of opportunity to get care at all, let alone appropriate care.” –Parent Focus Group Participant

“I’m not sure if it’s us or them, but it is often adversarial. People want to do the right thing, but I haven’t seen us working together. Something has to change from the top down. A patient is a patient. It’s not territorial. It’s not marking the territory. In a perfect world we need a hybrid of both services.” –Mental Health Provider Focus Group Participant

A primary goal for the NYSTART program on LI will be to develop partnerships, along with improved capacity for service provision and clarification of roles and responsibilities in the system as a whole.

Themes

Reported commonalities by respondents include a need to improve information, communication and coordination of services to improve access and effectiveness, better integration of crisis services, need for training of first responders, and improved training for providers across all systems. A detailed description of each of these themes is presented below.

Theme 1: The need for information, communication and coordination of services to improve access to services for primary service users and families

Family members made a significant contribution to the analysis making up over 21% of on-line survey respondents, participating in two separate focus groups and completing 26 telephone interviews. Overall, they are much less satisfied than providers and others involved with the mental health or IDD systems who also participated in the survey.

Within the focus groups, family members express frustration at the lack of crisis services and feel that the lack of comprehensive, effective and coordinated services exacerbates this issue. In particular, families express frustration that access to services often decline after individuals leave school and state that there is a lack of meaningful employment and recreational activities available for their adult family members. They state that it is possible that this shortage of positive opportunities increase their family members’ need for crisis services. A more comprehensive analysis of service needs to address all quality of life elements are strongly recommended by family member respondents.

National trends indicate that access to work and meaningful life experiences are often hampered by lack of support for people with behavioral health challenges in the population as a



A program of the Institute on Disability/UCED, University of New Hampshire

whole, and this undermines their mental health. *The NYSTART program will focus on training and support to programs/providers that assist individuals to access to social, recreational and vocational /work based opportunities.*

Another element of the NYSTART programs is the provision of Comprehensive Service Evaluations (CSE), which is an evaluation that allows for an integrated bio-psycho-social analysis of service needs. CSEs will allow the NYSTART programs to contribute to the evaluation of transitional youth in a timely fashion to improve service effectiveness including access to needed services.

“Parents need more help in transitioning kids. They don’t know how to do it and services are not in place and that contributes to crisis. Parents need more training on what to do.”

-Family Focus Group Participant

“There is a lack of meaningful day time activities. My son sleeps all day and that exacerbates his bi-polar.” –Family Focus Group Participant

When asked their perceptions about the availability of IDD services in Region 5/LI, there is very little difference between the way IDD and mental health providers reportedly perceive OPWDD funded services. About 25% of IDD and mental health provider respondents feel that overall IDD services need to be developed within the community, this compared to over 45% of family member respondents. Family members cited residential and employment services as the areas of greatest need.

When asked about mental health services for their family member with IDD, 40% of family members respond that they do not know if the services exist and an additional 29% actual report that the services did not exist at all. **Less than one third (31%) of family member respondents reported that needed mental health services are available to their family members with IDD.**

Fifty-two percent of responses by family members, in open ended questions regarding the services that are most needed in their community, were related to improving access to meaningful and coordinated services for their family member.

“The need to help families navigate the various systems is imperative. OMH and OPWDD working together to expedite access is also an imperative.” -Survey respondent

“We need advocacy programs for parents. We need a real list of services for families to choose from. We need better activities for individuals.” -Survey Respondent



A program of the Institute on Disability/UCED, University of New Hampshire

“Many families are in the mind set of 24/7 group homes as the expectation, and need to be educated about other options. Supports need to be further developed for those with high needs to be able to live in the community with less than 24/7 staff supervision safely.”

- Survey Respondent

Families and self-advocates point to a need for services that contribute to an improved quality of life such as employment, recreation, transportation and social opportunities as an important contributor to their mental health. This was not the focus of provider respondents.

“We want services that make our lives better, like volunteer opportunities, recreational activities and especially work opportunities.” –Self-Advocate Focus Group Participant

The NYSTART program will provide an analysis of the individual’s system of support in the community and this includes both needs based and strength based relationships. The analysis is used as one instrument to assist in navigating the team to help improve the quality of the life of the individual service recipients. START advocates for meaningful and strength based life experiences as essential elements in promoting mental health.

For family caregivers participating in the telephone interviews whose family member has had access to mental health services within the past year, only 19% report that the mental health services available to them are actually the ones they feel they need. Ninety-six percent of families interviewed indicate that they are not given the option to choose between services and providers. Another significant finding is that 89% report that services that are available are not always convenient and easy to access. **Families report that they do not have as much choice as they would like when choosing a mental health service provider.**



A program of the Institute on Disability/UCED, University of New Hampshire

Table 4: Service Availability

Question	None at all	Very little	Some, but not as much as was needed/wanted	All that was wanted/needed	Did not know/Answer
Were the available services the ones needed?	23%	23%	35%	19%	0%
Was there opportunity to choose mental health services?	38%	35%	23%	4%	0%
Was their opportunity to choose provider?	50%	35%	8%	4%	3%
How convenient were services?	23%	27%	23%	23%	4%
Were services flexible enough to meet needs?	27%	15%	35%	23%	0%
How satisfied were you with outpatient services?	19%	8%	42%	31%	0%

Finding: Family members are asked to be involved in the coordination of care for loved one but do not feel heard by professionals they are working with. While more than half of family members surveyed feel encouraged by providers to take an active role in their family member’s treatment (56%), only 12% report that care providers always respond to their wishes. In addition, only 20% feel that the mental health providers always recognize the burden on family caregivers and less than half of the families interviewed (46%) report that they are getting all of the information or collaboration they need and desire.

Table 5 shows responses from family members participating in telephonic surveys when asked to rate the overall responsiveness of the system to the needs of their family member.



A program of the Institute on Disability/UCED, University of New Hampshire

Table 5: Service Responsiveness

Question	None at all	Very little	Some, but not as much as was needed/wanted	All that was wanted/ Needed	Did not know/ Answer
Encouraged to take an active role?	20%	8%	16%	56%	0%
How involved were you in treatment?	15%	4%	23%	54%	4%
Did services respond to wishes of family?	16%	28%	40%	12%	4%
How much say did you have in outpatient services?	8%	0%	50%	38%	4%
How satisfied were you with your role in treatment?	0%	8%	54%	38%	0%
How much did providers respond to your concerns?	12%	8%	38%	38%	4%
How much did providers take into account your opinions?	19%	4%	38%	38%	0%
Did providers recognize burdens on families?	36%	8%	32%	20%	4%
How much information did you receive about illness?	12%	19%	23%	46%	0%

Finding: Families identify the lack of coordinated care as a major obstacle.

Family members interviewed state that they want better coordination of services and planning that takes family preferences into account because they know what their family members need. When asked what advice they would give to service planners, **62% of the families interviewed want the system to focus more on integrated care that takes into account the mental health needs, IDD needs and the need for a positive life in the community for their family member.** Most family members interviewed cite a lack of willingness to listen to families, poor coordination between the two systems and long waiting lists for some gaps in effective service delivery.



A program of the Institute on Disability/UCED, University of New Hampshire

“Listen to the parents, and let us voice our opinion.” -Parent of an individual with IDD

“Providers don't listen to families; they shut families out and there is no family centered care. There must be family centered care within any IDD or mental health initiative.” -Parent of an individual with IDD

“Service providers don't listen to what parents have to say about their child's well-being and act as though the parents are not as educated as they are.” -Parent of an individual with IDD

Theme 2: There is a need to increase capacity to effectively intervene in times of acute crisis

The next theme to emerge from the analysis is the need to increase capacity to effectively help individuals experiencing an acute crisis. The reported issues in examining crisis services include a lack of understanding about the role of each part of the system in crisis situations and a lack of capacity to provide what is needed.

Respondents representing MH and IDD providers had similar opinions with regard to crisis response services in Region 5/LI. Of all mental health services, IDD and MH providers rated these services as least available with only 43% of MH providers and 38% of IDD providers feeling that crisis services are always or mostly available when needed. Family member respondents' perception of availability of crisis services drops significantly, with only 23% of respondents reporting crisis services as mostly or always available.

While all groups rated crisis services as the least available mental health service, respondent groups cite very different reasons for the lack of availability. Mental health providers cite the primary barrier as a lack of collaboration with OPWDD in getting appropriate placements for individuals after discharge from hospital. IDD providers express concern that individuals with IDD are excluded from mental health services or only given minimal treatment because their issues are seen as behavioral rather related to a mental health need. Family members report that both the IDD and MH systems as inadequate with regard to needed capacity and that there is a lack of understanding about IDD among mental health professionals.

MH inpatient providers report a reluctance to admit individuals with IDD into their facilities because the individuals often have long inpatient stays beyond what they consider necessary. They point to the need for a stronger coordination of services before, during and following an in-patient hospital admission.



THE CENTER FOR
START
SERVICES

A program of the Institute on Disability/UCED, University of New Hampshire

“Certainly we do our best to stabilize the patient but it is a placement issue. It is typically a family or group home saying that they can no longer care for the person. This leads to longer length of stays across the board. It is disposition problem.” -Hospital Provider Focus Group Participant

MH inpatient providers report that they often have very little information on the needs of an individual with IDD when an admission to their facility is requested and feel that they can often be used as a “back-up placement option” when the needs of the individual are too great for the residential setting or family.

“As a nurse who has worked in the hospital, there is a disconnect between the two (systems). Psychologists are not coming to the hospital to help. There is no connection and no information from the staff. There is a lack of ownership when they come to the hospital.” -Hospital Provider Focus Group Participant

IDD providers cite a lack of willingness by mental health professionals to accept individuals with IDD into crisis services as a barrier to receiving quality services. One residential provider shares the following example:

“We had a long-time resident who had declining mental health and there was increasing difficulty supporting him in the home. We felt that he needed inpatient treatment and could not find a psychiatric hospital that would take him so the staff took him to the ER, where he attacked a nurse. The ER reported the agency to OPWDD for abandonment. The agency was told that the consumer could not be admitted to a psychiatric unit because he was non-verbal and couldn’t participate in group therapy”. – IDD Residential Provider Focus Group Participant

The online survey lists five questions specifically designed to assess participants’ views on the system’s capacity to respond to crises.

These are:

1. Mobile Crisis Services: Are available first responders trained in mental health for people with IDD?
2. Are there crisis stabilization/hospital diversion beds?
3. Are there community-based psychiatric inpatient beds?
4. Are there out-of-home crisis respite services?
5. Crisis Intervention Services: Are there people to call (other than police) to assist in a crisis?

Overall, crisis intervention services are rated as not available by 31% of respondents. As seen in Table 6, an additional 34% of all respondents report that they do not have enough information about crisis services to answer this question. Family members are 16% less likely to perceive crisis services as



A program of the Institute on Disability/UCED, University of New Hampshire

available when compared to IDD and MH providers. **This suggests that a majority of Region 5/LI citizens may not have information on who to call or where to go in times of crisis.**

Table 6: Availability of Crisis Services

Availability of Crisis Services			
	Available	Not Available	Don't Know
Mobile Crisis Services	39.24%	27.43%	33.33%
Crisis Stabilization/Hospital Diversion Beds	23.81%	33.33%	42.86%
Out-of-Home Crisis Respite Services	39.39%	29.44%	31.17%
Community-Based Psychiatric Inpatient Beds	28.13%	30.80%	41.07%
Crisis Intervention Services	44.16%	32.90%	22.94%
All Crisis Services	34.94%	30.78%	34.27%

The table below shows the percent of providers and family member respondents who rated each type of crisis service as always or mostly available in their community.

Table 7: Availability of Service by Respondent Group

Availability of Service (% all or some of what is needed)			
Service	MH Providers	ID/DD Providers	Families
Mobile Crisis Services	42.86%	43.30%	27.08%
Crisis Stabilization/Hospital Diversion	27.91%	28.42%	10.87%
Out-of-Home Crisis Respite Services	40.00%	47.92%	29.79%
Community-Based Psychiatric Inpatient Beds	40.00%	26.32%	17.39%
Crisis Intervention Services	62.50%	44.90%	28.26%
All Crisis Services	42.65%	38.17%	22.68%

Results from the on line survey indicate IDD providers are the most likely to have information about crisis services. 39% of mental health providers responded “don’t know” compared with 50% of families and 21% of ID/DD providers. All groups are least likely to know about community crisis bed availability or hospital diversion services when compared to knowledge of other crisis service options.



THE CENTER FOR
START
SERVICES

A program of the Institute on Disability/UCED, University of New Hampshire

Table 8: Availability (Don't Know) of Service by Respondent Group

Availability of Service (% Don't Know)			
	MH Providers	IDD Providers	Family Members
Mobile Crisis Services	42.86%	18.56%	52.08%
Crisis Stabilization/Hospital Diversion Beds	51.16%	27.37%	60.87%
Out-of-Home Crisis Respite Services	45.00%	14.58%	44.68%
Community-Based Psychiatric Inpatient Beds	32.50%	34.74%	54.35%
Crisis Intervention Services	22.50%	12.24%	39.13%
All Crisis Services	38.80%	21.50%	50.22%

Psychiatric inpatient care and crisis intervention services

Respondents reportedly have differing opinions with regard to availability for inpatient psychiatric beds and crisis intervention services. Mental health providers were 20% and 25% respectively more likely to view these as more available than families or IDD providers. This was echoed in the focus group responses in which mental health providers often feel that hospitals and emergency rooms are utilized before other community based services. One mental health provider describes this:

“There is a real lack of understanding between the OMH and OPWDD providers. Mental health providers view an acute stay for someone having an acute psychiatric episode. On the OPWDD side, they request hospitalization because of aggressive behavior. It doesn’t meet the medical necessity and the behaviors can be addressed in the milieu”.

–Mental Health Provider Focus Group Participant

It is important to note that the New York State claims data portrays high utilization of hospital emergency room use for a small number of individuals having actually accessed inpatient beds.

Families report that individuals are not getting needed crisis services for mental health issues because they have IDD.

“A psychiatrist told me that they couldn’t help my daughter because she did not understand her illness.” –Family Focus Group Participant

“I was told by the doctor, ‘he doesn’t belong here.’ They put him back on Risperdal and sent him home.” –Family Focus Group Participant

In addition to the concerns about access to crisis services for individuals with IDD, many survey respondents report that the geography of Long Island made services particularly difficult to access. A shortage of hospital beds particularly in Suffolk County is also noted by both survey respondents and focus group participants alike. One parent noted the geographic difference between Suffolk (90 miles



A program of the Institute on Disability/UCED, University of New Hampshire

long) and Nassau (13 miles wide) counties as problematic in accessing crisis services in a timely way. This parent also states that psychiatric crisis care does not attract the same attention as a major health issue, such as cardiac or cancer care might.

“MH Crisis has two providers on Long Island. The geography of Long Island limits availability to use of these services in a timely way.” -Survey Respondent

“Mobile Crisis’ biggest challenge is response to emergencies due to the large areas of coverage each program is responsible for. It is a quality service, but it is stretched thin.” -Survey Respondent

“There is 50% per capita typical hospital capacity in Suffolk County” -Survey Respondent

“Nassau County has a plethora of beds, but those beds are county funded and the community can’t place Suffolk County individuals in that facility.” –Family Focus Group Participant

Families are not satisfied with the availability of crisis services.

On-line surveys and phone interviews drew consistent responses from family member cohorts. According to the information gathered through phone interviews, a large majority of families (89%) feel that there are little or no options for crisis services outside of the hospital. Of those families who have utilized the hospital in the past year, 43% report that those services have not been helpful.

Table 9: Crisis Service Availability

Question	None at all	Very little	Some, but not as much as was needed/wanted	All that was wanted/needed	Did not know/ Answer
Are there crisis options outside the hospital?	58%	31%	4%	0%	8%
If used, were inpatient services helpful?	43%	0%	14%	43%	0%
How much information did you receive about what to do in a crisis?	50%	19%	8%	23%	0%
How much information did you get about whom to call in a crisis?	58%	23%	0%	19%	0%
How much crisis help was available nights or weekends?	24%	40%	20%	0%	16%



A program of the Institute on Disability/UCED, University of New Hampshire

Theme 3: Need to Increase training to police and other 911 responders across Long Island

One theme that emerged along with the need for improved access to crisis services on Long Island, is the need to increase training and knowledge of both IDD and mental health issues among police and other 911 responders. In particular, IDD providers and families participating in the focus groups report that the lack of availability of trained MH crisis responders leads to frequent use of 911 to deal with psychiatric emergencies. This issue is viewed by participants as a major contributor to increased incarceration of individuals in crisis and in some cases an increase in crisis situations, since involvement with law enforcement personnel can be frightening to individuals.

One residential provider explains:

“The police bring a temporary calming influence to the scene, because the individuals are frightened, but once they depart, there is no sustained plan or supports in place after a crisis. The situation usually just gets worse”. –IDD Provider Focus Group Participant

Many families, in particular, worry that the use of police to handle crisis situations could lead to tragedy.

One parent and former police officer stated:

“I shudder at the idea of 911 called to deal with behaviors because police don’t have enough training to deal with folks with ID/DD. Some cops can think beyond the obvious and some can’t and that can have disastrous consequences.” –Family Member Focus Group Participant

“In one incident the police came in as a result of an incident involving aggression and the police came in and didn’t know the individual had a disability and then apologized for ‘taking the person down’.” –Self-Advocate Focus Group Participant

Several IDD providers noted that the most successful law enforcement interactions involved police and EMT personnel that have frequent and routine contact with providers. Many stated that they offer information and informal training to local police in order to ensure safer responses to crises. However, there was widespread agreement that broader, more standardized training for first responders is needed.

A major focus of the NYSTART program will be to work collaboratively with all parties to address the need for appropriate, accessible and reliable crisis response and acute care, with the aid of the NYSTART team that will include 24 hour response.



A program of the Institute on Disability/UCED, University of New Hampshire

Theme 4: Increase access to expertise and training and consultation on mental health needs of individuals with IDD across both service systems

With regard to training there were differences in the perceptions of on-line survey respondents and individuals who participated in focus groups.

The lack of expertise about the mental health needs of individuals with IDD is cited as a barrier by focus groups. For self-advocates, training is the number one concern expressed with 60% of comments related to the need for improved training for staff in both systems.

However, the majority of Mental Health providers do not report that more training for MH providers is needed. This may be explained in part by other information provided by the MH provider cohorts, who do not view the majority of the problems as unmet MH needs for people with IDD who request help.

MH cohorts report the need for the IDD system to improve capacity to take better care of individuals they serve as a primary issue with regard to training.

“Over the last 20 years there is an inability of the system of (IDD) providers to deal with aggression. This is universal, but when the person does enter the hospital, they think it is someone else’s problem”. -MH Provider Focus Group Participant

“The biggest need is for people to understand this population”. -Family Member Focus Group participant

On line survey outcomes for training needs

The online survey lists three questions specific to training and expertise:

- 1) Are MH staff trained and qualified to support individuals with IDD?
- 2) Is technical support in IDD available to MH providers?
- 3) Is consultation provided by specialists in the field?

When asked in the on-line survey, ‘Are MH staff trained and qualified to support individuals with IDD?’ a significant number of mental health providers (73%) rate the training as all or some of what is needed. This is the highest positive rating for any service by mental health providers. More than half (59%) of IDD providers also rate the training of mental health staff as all or some of what is needed. While this result is less robust than the MH provider’s view of their training, it is significantly higher than the impression of service recipients and their families. Only one third (36%) of families feel that the training available to MH personnel is all or some of what is needed.



A program of the Institute on Disability/UCED, University of New Hampshire

As with all survey questions, people responding to these questions were instructed to rate them for ease of access (does the service exist and is it available), appropriateness (does it match the needs), and accountability (is it satisfactory, helpful). Results show that just over half (55%) of all stakeholders report that IDD-trained mental health professionals are available and 48% believe the options available match their needs. As displayed in the table below, providers are more likely to feel that training is available than family members.

Table 10: Staff Training by Respondent

Group Responding	Staff Training (% all or some of needed)		
	Available	Matched Needs	Helped
MH Providers	73%	66%	66%
ID/DD Providers	59%	48%	48%
Family members	36%	39%	33%
Overall	55%	48%	46%

Consultation

Tables 11 and 12 (below) demonstrate the respondents’ perceptions related to the availability and helpfulness of consultation. Service consultation is rated the least available and helpful. It is noteworthy, that there is very little difference in the percentage of individuals who feel that consultation is available and those that reported it as helpful. **This suggests then when consultation services are available, they are perceived as helpful.**

When asked to rate the availability of consultation services, MH and IDD provider respondents answer “don’t know” nearly 27% of the time as compared to 33% of family members reporting similar perceptions.

“There is very little training for staff about individuals diagnosed with both MH and DD, unless a staff member has had experience with both populations. These staff members may have a little more understanding of both populations and can somewhat serve them better. But still, individuals with DD may have other underlying issues and have some of their MH symptoms misdiagnosed due to their intellectual disabilities.” - Survey Respondent



A program of the Institute on Disability/UCED, University of New Hampshire

As seen in Table 9, MH providers are less likely to see service consultation as a need to their system. This may be an indication of the role they perceive MH services have in supporting individuals with IDD. However, when expertise is provided it appears to have been viewed as helpful for more than 50% of the responders.

Table 11: Service Consultation by Respondent

Group Responding	Service Consultation (% all or some)		
	Available	Matched Needs	Helped
MH Providers	63%	66%	68%
ID/DD Providers	38%	37%	38%
Family members	31%	29%	31%
Average (all respondents)	41%	41%	41%

Table 12: Clinical Consultation by Respondent

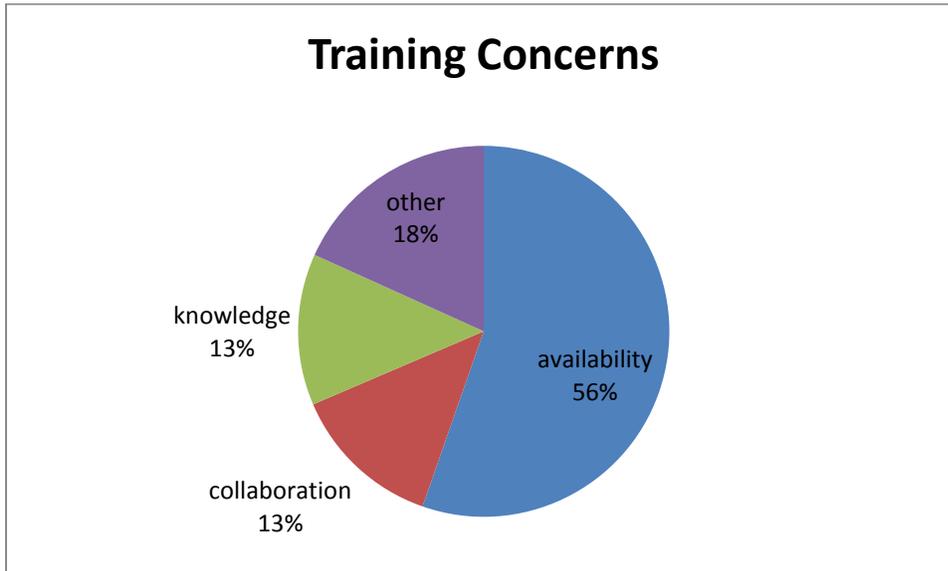
Group Responding	Clinical Consultation (% all or some)		
	Available	Matched Needs	Helped
MH Providers	63%	60%	59%
ID/DD Providers	64%	55%	56%
Family members	44%	44%	43%
Average (all respondents)	57%	52%	50%

All survey respondents who rated a service area’s availability as ‘None’ or ‘Very Little’ were asked to provide an explanation for that response. These responses help to identify the perceived gaps in training and consultation across Long Island (see Figure 6). **More than half (56%) of the individuals completing the survey reported that trained providers are not available where they live, or when they are, they are unable to meet the demand.**

Other reported training concerns include a lack of collaboration between the service systems (13%) and a lack of knowledge about co-occurring mental health and IDD (13%). These trends were also identified through focus group discussions.

A program of the Institute on Disability/UCED, University of New Hampshire

Figure 6: Training Concerns (reported through on-line survey)



The following are a sample of survey comments related to training concerns.

Availability (55%):

“There is a lack of training across the board for working with individuals whom are dually diagnosed.” -On-Line Survey Respondent

“There is little available training within the higher education programs that address dual diagnosis involving ID/DD folks.” -On-Line Survey Respondent

“The few specialists in the field have a back log. More are needed.” -On-Line Survey Respondent

Lack of Collaboration (13%):

“It has not been my experience that there is a great deal of training for MH staff to support individuals with ID/DD. Most programs services are geared to treat one or the other.” -On-Line Survey Respondent

“There are very little services available to individuals with a dual diagnosis. The two systems run very differently and many times MH staff and programs are not trained to work well with ID/DD population.” -On-Line Survey Respondent



THE CENTER FOR
START
SERVICES

A program of the Institute on Disability/UCED, University of New Hampshire

“Staff indicates that they do not feel comfortable or capable of serving individuals with DD and look to transfer dually diagnosed to the DD system.” -On-Line Survey Respondent

“MH and ID/DD operate in silos, very little interrelationship or consultation.” -On-Line Survey Respondent

Lack of Knowledge (13%):

“People need to realize that folks with ID can have mental illness and can benefit from MH services. Also, not all behavioral issues are MH related. Need to have much more cooperation between the two services.” -On-Line Survey Respondent

“There is very little training on how to support individuals with both MH difficulties and ID/DD. Most training consists of how to support individuals’ needs based off of their ID/DD diagnoses.” -On-Line Survey Respondent

“Typical response when ID/DD folks are taken to Psych ER is ‘it’s behavioral’ with little consideration to the possibility of the complexity of the individual and their diagnosis.” -On-Line Survey Respondent

The lack of training to focus on IDD and co-occurring mental health conditions has emerged as a primary concern for families and service users/self-advocates accessing the system, and much of the training concerns expressed by service users focus on the need for mental health training for IDD staff. In particular, self-advocates feel that they can often be better supported if service providers understand and are more willing to address their mental health needs in residential and day program settings. One self-advocate describes how his residential staff feels uncomfortable when he wants to talk about his how he is feeling and instead suggest that he wait and speak to his therapist. This self-advocate states that the time he has with his therapist is not enough.

“I see a therapist 30 minutes a week and that is not enough. When I’m having a hard time, my staff refer me to the therapist instead of helping to support me during the crisis.” -Self-Advocate Focus Group Participant

Another service user describes being without support following the death of her mother.

“I’m a human being dealing with this (loss of Mom) and I get no support and no one wants to talk about my feelings. I don’t like suffering in silence”. -Self-Advocate Focus Group Participant



A program of the Institute on Disability/UCED, University of New Hampshire

The lack of available and effective training is also cited by all respondents as the primary reason that other mental health services such as crisis services and outpatient treatment are not accessible or effective for this population.

“Most of professionals who work with individuals with ID/DD do not get sufficient training on also indicating whether an individual is exhibiting MH symptoms.” -On-Line Survey Respondent

Another important element of NYSTART will be the implementation of a professional learning community along with Certified and trained START Coordinators to provide consultation, training and expert assistance to the community as a whole.

Theme 5: Increase access to outpatient mental health services

The online survey addresses several areas relating to outpatient mental health services. These include:

- 1) Outpatient Mental Health: Is it available to individuals with IDD?
- 2) Outpatient Psychiatry: Are there psychiatrists with training in IDD?
- 3) Diagnostic Assessment: Are there individuals trained to diagnose co-occurring MH and IDD?

Overall, these services are seen as more widely available to this population than crisis services with an average of about 54% of respondents rating them as always or somewhat available.

Table 13: Availability of Outpatient Mental Health Services by Respondent

Availability of Outpatient Mental Health Services (% all or some)				
	MH Providers	IDD Providers	Family Members	All Respondents
Outpatient Mental Health Therapy/Counseling: Group or individual	61.90%	60.00%	43.14%	55.88%
Outpatient Psychiatry: Psychiatrists with training in IDD	57.50%	67.00%	29.41%	53.75%
Diagnostic Assessment: Individuals trained to diagnose co-occurring MH and IDD	63.41%	53.13%	43.48%	53.51%
All Outpatient Services	60.94%	60.04%	38.68%	54.38%

Survey questions eliciting information from family members regarding availability and choice for outpatient psychiatry show similar trends as demonstrated throughout this report. Providers are 20%



A program of the Institute on Disability/UCED, University of New Hampshire

more likely to report services available than family members. Since families represent service users, often accompany them to appointments and assist with accessing necessary services, their lack of perceived service availability is significant. While some providers may view the resources as adequate this is not the experience of those who use them. Service users cite long waiting lists and poor training on issues related to IDD for mental health professionals as the primary concerns.

- “It is very difficult to find a prescriber that is comfortable working with this population. They somehow see themselves as not qualified, however, if they are not, who is? I think mandatory rotations for MD Psychiatry Residents and NPs in working with the ID/DD population would help, as well as readily available training.” -On-Line Survey Respondent
- “I think there are very few psychiatrists with this type of expertise. I know of only 2 or 3 on all of Long Island.” -On-Line Survey Respondent
- “Need more help. There are not enough service providers and the ones that are available are filled to the max and not taking any new patients.” -On-Line Survey Respondent

Increased access to outpatient services for people with IDD and behavioral health needs will be an important goal of the NYSTART team and will occur through a collaborative process fostered by the START network and linkages.

Other Findings

Region 5/LI survey respondents were most positive about special education and early intervention services with only 13% of all respondents (less than 10% of families) indicating that these services need to be further developed. As previously stated, however, both survey respondents and focus group participants indicate that IDD services were less available for adults. **There is a strong need described by families for improved transitional supports from child to adult service systems.**

Overall, those people completing the on-line and telephone surveys have the perception that IDD services are more available than mental health services. **On average, 74% of respondents surveyed feel IDD services are available in their community (work or work well) as compared to responses to similar questions measuring the perception of availability of mental health services (46% of respondents perceive that MH services are available to them).**

Behavioral health crisis services were rated by respondents as most in need of development (42%), consistent with earlier findings that many Long Island residents do not have the support they need to effectively manage crisis situations.



A program of the Institute on Disability/UCED, University of New Hampshire

In addition to special education and early intervention, the services in which the highest percent of individuals indicate are working well are day habilitation (32%) and service coordination (30%).

However, the majority of respondents express a need to improve capacity in all services provided for individuals with IDD and behavioral health needs, especially adults.

Table 14: IDD Services

IDD Service	Works well	Works, but could be strengthened	Needs to be developed
Facility-Based Residential Services-ICF/DD	24.31%	53.67%	22.02%
Residential Supports-Supportive apartments (less than 24 hour)	25.84%	46.89%	27.27%
Residential Supports-Home and Community-based Supports	24.43%	46.61%	28.96%
Community Habilitation, Respite	26.27%	47.47%	26.27%
Day Habilitation Services	32.13%	52.04%	15.84%
Supportive Employment (SEMP)	19.00%	53.85%	27.15%
Employment Opportunities	22.27%	46.72%	31.00%
Transportation Services	15.38%	49.57%	35.04%
Self-Direction	18.22%	55.61%	26.17%
ID/DD Service Coordination	30.26%	51.75%	17.98%
Medical Services	26.58%	56.31%	17.12%
Clinical Services (Article 16)	25.89%	51.78%	22.34%
Crisis Intervention Services	16.59%	41.71%	41.71%
IDD Behavioral Supports	18.60%	46.98%	34.42%
Family Respite-In-Home Respite	14.08%	48.83%	37.09%
Family Respite-Facility-based (weekend/vacation)	15.96%	49.30%	34.74%
Special Education	29.86%	57.01%	13.12%
Other Therapies (music, recreation)	13.27%	47.35%	39.38%
School-based Supportive Therapies	22.54%	56.34%	21.13%
Early Intervention Services	33.02%	53.77%	13.21%

As with mental health services, families are the most likely subgroup of respondents to feel that IDD services are inadequate and need to be developed further. Families most frequently cite residential services (68%), crisis intervention services (61%), employment services (51%), transportation services (46%) and respite (44%) as being the highest need area of development.



A program of the Institute on Disability/UCED, University of New Hampshire

This supports the earlier finding that families want a more coordinated system that takes into account all aspects of an individual's life. Within the focus groups, both families and providers express concern that the current IDD system is not equipped to deal with an increased demand for services.

“There is a coming tsunami within the system (IDD) as children transition into adult services and adults already being served age and require more significant supports”. –Family Focus Group Participant

One family member expresses concern that in a time of stretched resources START might negatively impact the current IDD system:

“START might push services too far in the mental health direction, which may inadvertently increase barriers and limit access to other services”. –Family Focus Group Participant

This concern is important to understand. Many families and service users experience stigma and barriers in the context of mental health issues in addition to IDD challenges, an issue continuously addressed by START programs.

NYSTART providers will advocate for attention to social acceptance, improvement of mental health and crisis services, but emphasize the importance of additional development of supports with expertise that promote independence and quality of life (e.g., vocational services, recreational opportunities). This is consistent with the mission of the START model and the positive, health promotion, strength-based approaches employed throughout.

The aforementioned findings make a compelling argument that, in order to address the needs of people with IDD and co-occurring mental health conditions, improvements in all levels of services and supports is needed, this is consistent with the START mission and philosophy.



A program of the Institute on Disability/UCED, University of New Hampshire

Conclusions:

The proper implementation of the START model can help to improve the system of support and address many of the issues identified in this report. All NYSTART programs will have consistent services across the state. Recommendations from the Region 1 and Region 3 pilots along with the NYC START system analysis will be incorporated into the Region 5 program development. Many of the recommendations below resulted from the systems analysis conducted in NYC, while some are unique to Region 5's contribution.

1. Attention to the promotion of mental health and well-being, including meaningful life experiences and engagement will be needed in addition to better treatment and support for those with mental illness and/or in crisis.
2. Active engagement with families and service users to ensure program effectiveness will be key to the program's success. Family/ self-advocate advisory boards should be developed for each region to assist in the implementation and improvement of START services across the state. This should not replace the stakeholder advisory board.
3. In home supports and family caregiver coaching will be key elements of the NYSTART program
4. NYSTART should focus on high-risk transitional youth in a timely fashion and conduct a Comprehensive Service Evaluation (CSE) at least two years prior to transition to the adult system to assist in the timely development and implementation of services and supports in the adult system.
5. The NYSTART program should establish operational, cross systems networks throughout the region through their regional teams. These networks will help to:
 - a) improve access to essential needed services and supports;
 - b) ensure services are appropriate and match services needed;
 - c) ensure accountability in the system as a whole to collaborate and improve overall services and treatment to the population; and
 - d) training across the system is needed to improve capacity in the community
6. Improved caregiver knowledge about specific services, including better communication about how to access existing services across systems is needed.



A program of the Institute on Disability/UCED, University of New Hampshire

7. Crisis intervention services must occur early on and with the input of caregivers and service recipients to ensure their effectiveness. Reduction of emergency rooms and emergency services overall should be a focus of the NYSTART programs.
8. Attention to the individual's life context, need -based and strength- based supports is needed.
9. Continuous methods to provide and receive feedback should be established. Data collection and analysis will ensure that evidence informed practices are being employed and are effective.

Next steps/Recommendations:

While the START model appears to match the reported needs in the system, the emphasis early on must be on engagement of the entire system to operate the program effectively. Following are steps to effective program development based on the needs reported in Region 5/LI:

1. Finalize the design of the NYSTART programs (specific recommendations are in the addendum to this report). In the request for proposals to provide NYSTART services, emphasis should be placed on the fact that START is an integrated behavioral health team that promotes strength based, person centered supports and services.
2. Focus on positive mental health and wellness approaches will be key for the successful provider of this program.
3. The development of a plan by the NYSTART team bidder to implement regional support networks will be key. The Center for START Services will work closely with the Regional Teams and other stakeholders to help with the establishment of START networks across Nassau and Suffolk Counties; however, existing relationships will be important to begin the process.
4. Development and implementation of the interdisciplinary professional learning community across LI and linked with other NYSTART programs must include technological support to foster access to training and consultation opportunities. The learning community should include family and direct support provider education and mentoring. The national START team will provide the needed training and consultation resources, including CME and CEU eligible study groups. Providers submitting proposals should have a plan to make these as accessible to as many stakeholders as possible.
5. NYSTART programs must work closely and collaboratively with all first responders already established on Nassau and Suffolk Counties to ensure effective crisis response. Roles and responsibilities must be clearly established and defined as part of this process and joint trainings will be needed. Providers submitting proposals should address this issue.



A program of the Institute on Disability/UCED, University of New Hampshire

6. NYSTART programs should link with NYC multi-modal consultation teams in development to assist with assessment of individuals with more complex needs.
7. NYSTART teams should attend established mental health and IDD provider meetings for a minimum of the beginning 18 months of development and operation to provide information and hear concerns. Providers submitting proposals should provide a plan to assure this occurs.
8. It is imperative that a review of inpatient mental health services occurs, including how to access and use them effectively. NYSTART teams should be oriented to all inpatient services in order to have a clear understanding of what can be provided on the unit. At the onset, NYSTART programs should establish that they will be there within the first 24 hours or the next business day to assist with discharge and treatment planning, support on the unit and ensure timely discharge from inpatient stays. Providers submitting proposals should include their plan for ensuring this occurs.
9. The NYSTART teams need to develop a plan as to how they will interface with the education system and local schools. The proposed provider should have a plan to make this happen.
10. Given the wide spectrum of the people needing services, the changing landscape with regard to research and training, and the commitment across providers and systems, it is suggested that any remedy going forward take into account what has been learned from the data collection and analysis of the needs of this population over time. Stakeholder and family advisory councils should be formed to help with this process. The proposed provider should have a plan to assure that this occurs.

It is suggested that these recommendations be incorporated in the request for proposal to ensure they are part of the program design.

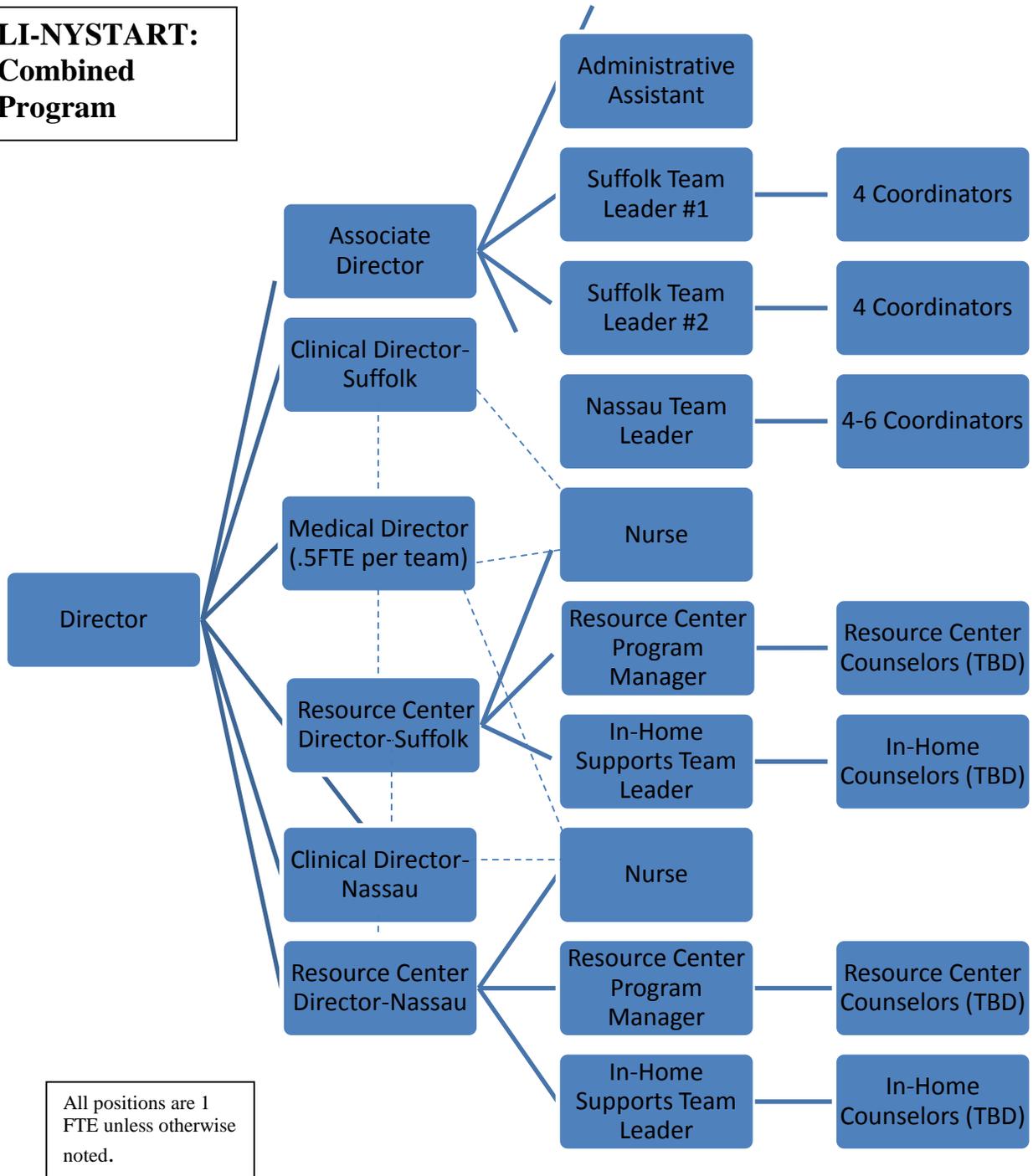
Recommended program design for NYSTART in Region 5/LI

The program design is a combined program which would include a Program Director and Associate Director that would oversee Suffolk and Nassau Counties. Together, they would be responsible for supporting three team leaders (2 in Suffolk and 1 in Nassau), two full time clinical directors (one in each county) and two Resource Center Directors (one in each county).



A program of the Institute on Disability/UCED, University of New Hampshire

**LI-NYSTART:
Combined
Program**



All positions are 1 FTE unless otherwise noted.



A program of the Institute on Disability/UCED, University of New Hampshire

References

- (1) <http://www.aidd.org>
- (2) Beasley, J., (1998); "Long term co-resident caregiving in families and persons with a dual Diagnosis; (Mental Illness & Mental Retardation)". *Mental Health Aspects of Developmental Disabilities*, Vol.1 (1), (10-16)
- (3) Beasley, JB & Kroll, J. (1999); "Family caregiving part II: Family caregiver-professional collaboration in crisis prevention and intervention." *Mental Health Aspects of Developmental Disabilities* Vol. 2(1), 22-26.
- (4) Beasley, JB (2000); "Family caregiving part III: Family assessments of mental health service experiences of individuals with mental retardation in the northeast region of Massachusetts from 1994-1998." *Mental Health Aspects of Developmental Disabilities*, 3(3).
- (5) NVIVO 10 for Windows. Copyright QSR International 1999-2014.
- (6) Tessler, R. and Gamache, G. (1995). *Toolkit for Evaluating Family Experiences with Severe Mental Illness*. Cambridge MA. Human Services Research Institute.
- (7) Beasley, JB & duPree, K. (2003); "A systematic strategy to improve services to individuals with coexisting developmental disabilities and mental illness: National trends and the "Connecticut blueprint" *The Mental Health Aspects of Developmental Disabilities* (pp. 50-59).
- (8) Beasley, JB (2004). "Importance of training and expertise to assess "what works" for individuals with intellectual disabilities" *Mental Retardation* (42)4 (310-311).
- (9) Joan B. Beasley (2007). Editor *U.S. Public Policy: Assessment of Services for Individuals with Developmental Disabilities and Mental Health Needs in Mental Health Aspects of Developmental Disabilities*, Volume 10-3.
- (10) Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities. Prevalence and associated factors. *Br J Psychiatry* 2007; 190:27-38.



A program of the Institute on Disability/UCED, University of New Hampshire

Appendix A: Data Collection Tools

1. Community Support Survey
2. Family Experiences Interview Schedule (FEIS)
3. Family Focus Group Questionnaire
4. Provider Focus Group Questionnaire



A program of the Institute on Disability/UCED, University of New Hampshire

Appendix B: Region 5/Long Island IDD/MH Task Force Members

Lauren Accovelli
Geri Athenas
Roseann Avella
Besa Bauta
Donna Bernard-Garone
Jacquelyn Best
Beverly Burke
Kathy Callahan
Bridget Cariello
Martha Carlin
Kevin Christman
Amy Cohen Anneling
Tim Coleman
AnnMarie Csorny
Ray DeNatale
James Dolan
Lino Faccini
Nicky Faranda
Mary Fasano
Charlie Fleisch
Yuan Gao
Alison Giangregorio
Maggie Hoffman
Michael Hoffman
Richard Kessler
Didier Labissiere
Julia Laevsky
Alison Loewy
Bob Lopez
Jamie Lusky
Terry Manzione
Gina Maranga
Mike Marzo
Susan McCarthy
Barbara McNamara
Cheryl Olson-Stricko
Joy O'Shaughnessy
Jillian Panni
Meredith Pieper



A program of the Institute on Disability/UCED, University of New Hampshire

Susan Platkin
Roy Probeyahn
Shiny Sajan
Christine Schulte
Anne Marie Sime
Jamey Simonetti
Astrido St.Surin
Margaret Stadnicky
Pam Stark
Eileen Taylor
Carla Vecchione
Marcia Vogel
Maura Wachsberger
Ralph Warren
Jason Watson
Susan Weigele



THE CENTER FOR
START
SERVICES

A program of the Institute on Disability/UCED, University of New Hampshire

Appendix C: Focus Group Protocols and Dates

Focus Group Protocols

Introduction: Introductions are made in order to gain better knowledge of the community and to foster positive relations between systems and the group facilitators. A short explanation of the purpose of the focus group will be provided.

Initial Assessment: The IOD has developed a questionnaire to collect information about IDD/MH services in the community. Participants in the focus groups will fill out the questionnaires when the focus group commences. Everyone will be given ample time and writing tools to complete the questionnaire, and there will be follow up conversation in regard to existing services and service needs.

Data Collection: After questionnaires collected the participants will be given the opportunity to expand on their thoughts in regard to questions about service delivery, service needs and training needs. This is also a time for IOD staff to learn more about families, providers, provider structure, existing systemic partnerships, and overall provider culture. While participants are sharing their thoughts and ideas, information will be recorded by an IOD staff member either in person or telephonically.

Final Question and Answer: In concluding the focus group all participants are given a chance to ask questions. Information will be given in regard to how results of the focus group will be used and how the final report will be distributed

List of Groups Conducted

Date	Group	Number of Participants
December 10, 2014	Crisis Coalition	7
December 10, 2014	Family Advocacy Group	10
December 11, 2014	IDD Providers (Residential)	9
December 11, 2014	IDD Providers (FSS)	10
December 12, 2014	Families	6
December 12, 2014	Self-Advocates	13
February 10, 2015	Mental Health Providers (Clinic)	10
February 10, 2015	Mental Health Providers (Residential)	11
February 11, 2015	Mental Health Providers (Hospital)	14



A program of the Institute on Disability/UCED, University of New Hampshire

Appendix D: Clinical Education Team Dates and Hosts

Clinical Education Team Methodology:

There were 5 CETs scheduled to occur between February and June, 2015 and were held for both NYC and Long Island. Agencies supporting individuals with IDD and co-occurring behavioral health conditions were asked to volunteer and then were selected at random to host the event in their borough in partnership with OPWDD and The Center for START Services. The agencies selected a team of their staff to participate in training conducted by the Center for START Services staff and to prepare and present a case using the CET methodology. Members of the National Center for START Services consultation and training team also participated at each of these events by providing didactic training based on the case being presented.

Below is a list of the CET events, hosts for each CET event, topics of the trainings and the number of stakeholders who participated either in person or remotely at each location.

List of Trainings Conducted

Borough	Date and Location	Host Agency	Training Topic	Estimated Number of Participants
Brooklyn	March 12, 2015 Brooklyn *Rescheduled from 2/2015 due to weather	Ohel Bais Ezra	MH Diagnostic Considerations in IDD	25
Manhattan	March 11, 2015	ICL, Inc	Klinefelter Syndrome	35
Staten Island	April 8, 2015	Heartshare Human Services of NY	Trauma and IDD	45
Queens	May 20, 2015	PSCH	Understanding ASD's and co-occurring mental health challenges	25
Long Island (held in Queens at PSCH)	May 21, 2015	Family Residences and Essential Enterprises (FREE, Inc)	Autism and Anxiety	40
Bronx	June 3, 2015	Unique People Services	Prader Willi Syndrome and Treatment Considerations	30