



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

New York City Service System Analysis

April 30, 2015

Executive Summary

In collaboration with the New York State Office for People with Developmental Disabilities (OPWDD) and local stakeholders (including family members, self-advocates, IDD and MH 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 New York City (NYC) for individuals with intellectual developmental disorders (IDD) and mental health needs. This was conducted in preparation for the planned implementation of START services in that region in fiscal year 2016.

Based on current census data, an estimated 400,000 (or 2% of the state population) of New York State (NYS) citizens have IDD. 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.

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 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.



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In October 2014, OPWDD convened a multi-stakeholder group of participants and asked them to form a task force, the NYC IDD/MH Task Force. This NYC IDD/MH Task Force was asked to assist with gathering information from across the city 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 in New York City in addressing the needs of individuals with intellectual/developmental disabilities and mental health needs/challenging behavior?
- How can the NYSTART program help to enhance NYC's existing service delivery system to improve services and supports to those in need?
- What should the program design of NYCSTART 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 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 20 family caregivers using a telephonic research-based survey. Finally, a Clinical Education Team (CET) training was held in several locations across the city to help begin the process of learning about case specific challenges and to inform the community about the START approach. Participants represented a broad range of stakeholders and included self-advocates, families, service providers, and first responders. Over 700 New York City 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 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



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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.

Region 4 represents 36% of the of the statewide OPWDD population. Based on the data provided and the number of people who reside in Region 4, an estimated \$39 million Medicaid dollars are expended in NYC each year for mental health services for this population. Improvements in services and outcomes in NYC can have a significant financial impact statewide.

The input from stakeholders portrays a system overall that seeks to improve with a need to gain consensus going forward. The results from interviews and surveys indicate significant differences in the way that mental health providers, IDD providers and service users view the current service system and what is most needed to improve service effectiveness. In addition, several common themes did emerge from all constituent groups as well as across all the collection methods, including those that reported direct and recent experiences.

While it is important to note that there is a great commitment on the part of stakeholders and some areas where people report good outcomes, the lack of collaboration between the mental health providers and IDD providers was reported to be the most prevalent issue. The other main concerns reported are the need for greater crisis supports; improved training for providers across systems, better access to inpatient and outpatient mental health services; and greater access to IDD services especially vocational training.

Conclusions:

1. The proper implementation of the START model can help to overcome many of the issues identified in this report.
2. NYC is diverse and this must be part of the approach to care and support in order to engage all of those in need. Diversity training must be part of START program development and implementation.
3. The NYSTART program should establish operational, cross systems networks throughout the city 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
 - c) ensure accountability in the system as a whole to collaborate and improve overall services and treatment to the population



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4. Training across the system is needed.
5. Crisis intervention services must occur early on and with the input of caregivers and service recipients to ensure their effectiveness.
6. Improved caregiver knowledge about specific services, including better communication about how to access existing services across systems is needed.
7. Continuous methods to provide and receive feedback should be established that includes data collection and analysis as ways to assure that evidence informed practices are being employed.

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 NYC:

1. Finalize the design of the START programs (specific recommendations are in the addendum to this report). In the request for proposals to provide NYCSTART services, emphasis should be placed on the fact that START is an integrated behavioral health team.
2. The NYCSTART Program should be run by mental health providers with expertise in IDD. It is important that the services not be isolated as part of the IDD system alone.
3. The development of a plan by the NYCSTART 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 NYC, however, existing relationships will be important to begin the process.
4. Development and implementation of the interdisciplinary professional learning community across NYC and linked with other NYSTART programs across the state 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 this as accessible to many as possible.
5. NYCSTART programs must work closely and collaboratively with all first responders already established in NYC 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.



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6. NYCSTART programs should work to establish regional multi-modal consultation teams to assist with assessment of individuals with more complex needs. This consultation team should be comprised of the START Clinical Director, START Medical Director, a neurologist, primary care physician, an occupational therapist and other specialists as needed. One team should specialize and be dedicated to consulting with teams serving children and the other adults. To maximize resources, NYCSTART teams may share resources as possible to implement these teams. It is highly recommended that they be provided in a Medical School setting. Providers submitting proposals should include their plan for addressing this, including costs and plans to bill for this service.
7. NYCSTART 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. NYCSTART 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, NYCSTART 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 NYCSTART 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. NYCSTART advisory councils should be formed to help with this process. The proposed provider should have a plan to assure that this occurs.
11. Publication and information about existing services and how to access them can be provided through the NYS OPWDD website and other communication mechanisms. All service providers need to know what is available and accessible as well as how to assist families and service users in getting needed resources and supports.



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

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Analysis of New York City 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 will occur through cross systems relationships, training, education, and crisis prevention and response in order to enhance opportunities for healthy, successful and richer lives. START programs are currently being piloted in Regions 1 and 3, with the expectation that it will be implemented in the New York City (NYC) region in fiscal year 2016. In addition to what is being learned from the pilot, direct feedback from local stakeholders on the existing system and what supports are needed is essential to this important initiative. Following is an analysis of findings through structured interviews, focus groups and on-line surveys, as well as clinical education team forums conducted in partnership between The National Center for START Services and local providers across the city. 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 (4).

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.



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In New York state, there are approximately 130,000 individuals receiving services through NYS OPWDD and almost 36% (N=46,577) of these individuals reside in New York City (Region 4). In order to better inform the implementation of START services for this large and diverse population, OPWDD requested a comprehensive assessment of the current system of care in New York City. The goals of this analysis were to learn about what is working in New York City as well as to facilitate dialogue and discussion amongst stakeholders on the gaps in the current system and how these can be improved through the implementation of START services. There are multiple systems that must work together to foster success in this effort.

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.

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-



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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 NYCSTART 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 in New York City in addressing the needs of individuals with intellectual/developmental disabilities and mental illness/challenging behavior?
2. How can the NYCSTART program help to NYC enhance the existing service delivery system to improve services and supports to those in need?
3. What should the program design of NYCSTART 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 clinical education team meeting forums in each borough.

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 NYC IDD/MH Task Force (see Appendix B) played a key role in distributing the survey across NYC 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.

The estimated number of individuals served in NY State by OPWDD is 130,000. Of those individuals about 36% (N=46,577) reside in Region 4 (NYC).

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.



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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 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



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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 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 4 represents 36% of the of the statewide OPWDD population. Improvements in services and outcomes in NYC can have a significant financial impact statewide. Based on the data provided and the number of people who reside in Region 4, **an estimated \$39 million Medicaid dollars are spent in New**



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York City 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 NYC with a variety of constituents. Each focus group represented a specific type of constituency including: self-advocates (people who use services); family members; mental health service providers; hospitals; IDD providers; Medicaid Service Coordinators (MSCs); and staff from the Administration for Children’s Services (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 NYCSTART 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 on-site. 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 NYCSTART occurred in several forums over a twelve-month period prior to these sessions.

Method 3. Online Survey

An NYC IDD/MH task force was assembled and this Advisory Group reviewed, helped to revise and distribute the electronic survey link to constituents across the city 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 NYC as possible with experiences to share regarding the IDD/MH system.

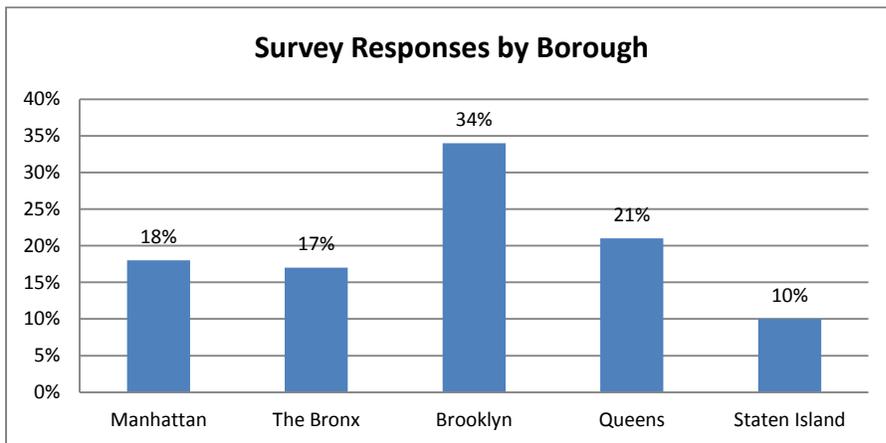


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In examining overall mental health service experiences for individuals with IDD in NYC, the analysis focused on three primary areas that must be aligned to provide effective services: Access (timeliness, location, ability to use), appropriateness (do they 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.

In all, a total of 313 NYC citizens responded to the survey between December 2014 and February 2015. The response was fairly evenly distributed across all five boroughs with Brooklyn having a slightly higher rate of response (34%) than the other boroughs. Staten Island had the lowest rate of response with only 10% of respondents. Figure 1 below shows the percent of individuals from each borough who responded to the on-line survey.

Figure 1: Online Survey Responses by Borough



The overall response rate was significantly lower than expected. Numerous reminders about the survey were distributed to task force members, but the low number of responses suggests that the survey was not broadly distributed to potential participants. In particular, the lack of respondents who identified themselves as direct care professionals in either system was markedly absent. An issue that may have contributed to the lower response rate is the diversity of the community. While the survey was available in several languages, the vast majority of people (99%) responding took the survey in English. The four non-English responses were in Korean, Chinese, Urdu and Spanish. A copy of the survey can be found in Appendix A of this report.

The majority (63%) (N=198) of people who participated in the online survey were IDD and Mental Health Service Providers. IDD providers made up approximately 86% of this group, while mental providers

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made up the remaining 14%. The providers reported significant experience in the field with an average of just over 18 years of service. This suggests that the individuals responding have significant knowledge of the current service system in NYC. 25% (N=78) of the people who completed the online survey are family members and 1% are individuals who use the service system. 12% (N=37) of persons responding to the survey listed as “other” report very diverse roles within the service system including educators, advocates and government employees. It is important to note that while the survey numbers were lower than was expected, other methods described later allowed for representative groups to have input through the focus group and phone interview processes.

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

Figure 2: Online Survey Respondent

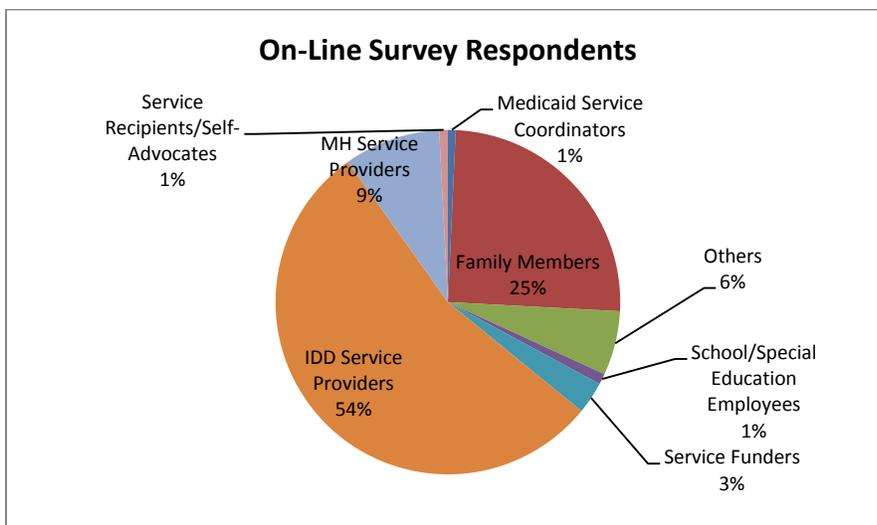
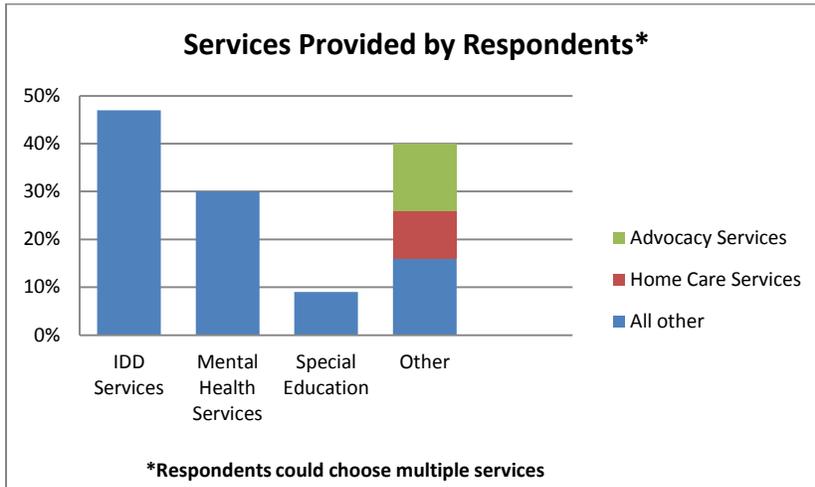


Figure 3 below shows the types of services provided by people who responded to the online survey. For individuals who chose “other,” a breakdown of the most common responses is included. The remainder of services included in this category is medical, legal, child protection and recreational services.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



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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 20 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.

Description of Family Member Phone Interview Respondents

Survey respondents were recruited across the city with the assistance of advocacy organizations, family support networks and provider organizations. Similar to the response rate of the online survey, the



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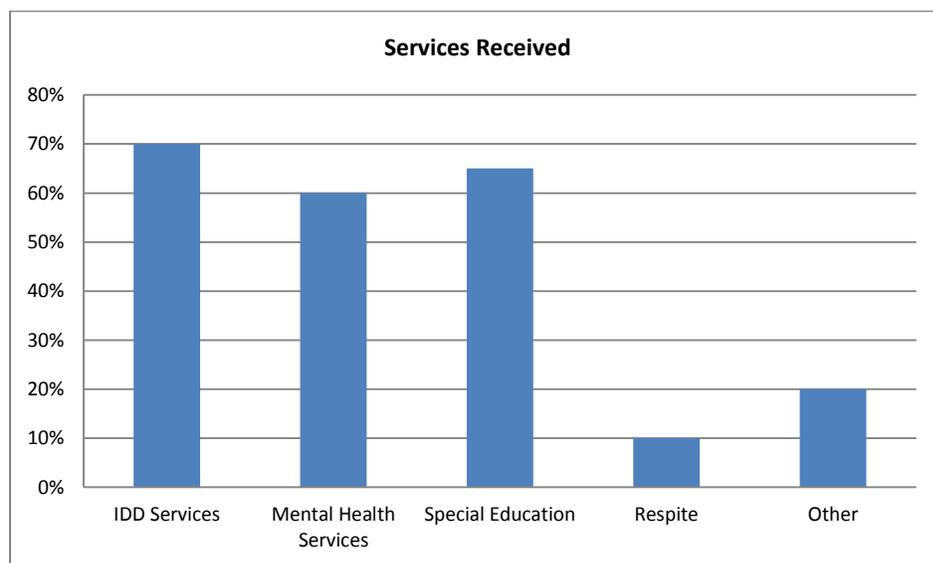
response was lower than anticipated and well short of the original goal of 50 family phone interviews. While the advocacy organizations were asked to put notices on social media or their websites, very few interview participants contacted IOD staff directly in order to take part in the interview process. Interview participants represented all boroughs in the city except Staten Island.

90% of the survey recipients were parents of an individual with IDD. 89% of respondents were female with an average age of 54. The majority of respondents (89%) reported having some college education and 44% were working either full or part-time. 60% reported a family income of at least \$50,000 annually. 68% reported that they considered their own health to be good; however, none reported their own health to be excellent.

Survey recipients were asked to share minimal, non-identifying demographic information regarding their family member with IDD. In 63% of the interviews conducted the family member with IDD was male with an average age of 26 years old. This is an interesting finding because it is consistent with trends of individuals 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 a break-down of the services currently received by survey recipients and their family members. While 60% of the individuals are currently receiving mental health services, there was a wide variation in the locations where those services were being provided, as seen in Figure 5 below.

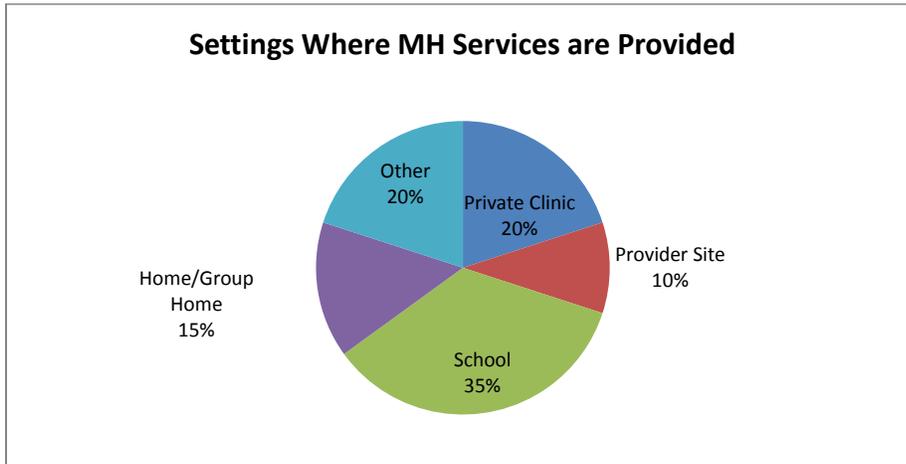
Figure 4: Types of Services Received





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Figure 5: Settings Where Services are Provided



Method 5. Clinical Education Team Demonstrations

Due to the high level of interest in the START model and the desire of NYC stakeholders to participate in training and other educational opportunities, Clinical Education Team (CET) demonstrations were scheduled to occur throughout the time in which this analysis was conducted. 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. However, it is expected that the discussion will generate ideas about possible remedies to improve services and clinical outcomes to explore for the individual presented.

There were CETs scheduled to occur in all five boroughs of New York City between February and June 2015, with over 180 participants registered to attend. While not all have been completed, feedback from the trainings in Brooklyn, Manhattan and Staten Island helped to inform the themes and recommendations presented throughout this report. See Appendix D for a list of CET dates and host agencies.

Integrated Analysis of Findings

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

It is important to note that there is a lack of consensus with regard to who in the system needs to change and what needs to occur between constituents represented. The overarching finding is that mental



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health providers, IDD providers and service users have differing perspectives on what is needed to improve service effectiveness.

While Mental Health providers see the gaps as primarily in the IDD system, the IDD system providers identify lack of access to mental health services as a major obstacle in the community system. In addition, the least satisfied respondents are families and service users who report a lack of services and supports with expertise across all system areas.

“For a mental health crisis there is nothing. There is a crisis intervention team but they are not sure what to do, and we can’t access them when they need them.” –Parent Focus Group Participant (translated from Spanish)

“The need is to have trained clinicians even in a hospital setting. There are no clinicians that can deal with this population. There is such a need, but it’s like pulling teeth. Any time you mention that the kid has a DD, you can guarantee that they will be sent back home.” –Parent Focus Group Participant

A primary goal for the NYCSTART program will be to develop partnerships, clarity and a common language with regard to roles and responsibilities in the system as a whole.

Themes

Although the conclusions and potential remedies with regard to responsibility and accountability in the service system differ among stakeholders, there are several areas of consensus. These commonalities include a need to improve collaboration between the mental health and IDD systems, better access to effective crisis services, improved training for providers in all systems, and improved communication with families and other service providers with regard to mental/behavioral health services. A detailed description of each of these themes is presented below.

Theme 1: The need to improve collaboration between stakeholders

Within the focus groups, the most common, overall challenge cited is a lack of effective collaboration between the MH and IDD service systems. The issue is prevalent among all the groups interviewed regardless of the method used to obtain the data.

Stakeholders that participated in the CETs stated that cross systems collaboration between mental health and IDD services is challenging and often a barrier to treatment for individuals with IDD and behavioral health needs. The organizing and planning of the CET events was also challenging to coordinate across systems. Participants were not always aware of local providers in their borough who provide similar services, making it difficult to get a broad array of stakeholders represented at the events.



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- “No sense of collaboration between the two agencies. Either an OMH or OPWDD problem. No sense of working together to figure out what to do with the patient.” -Hospital Focus Group Participant (Psychiatrist)
- “Need collaboration between the MH and DD system. It shouldn’t be so cut and dry. There has to be some open door between the two systems. Some people with IDD need both sorts of supports.” -IDD Provider Focus Group Participant
- “Biggest barrier—lack of cross system collaboration. These are NYC children and it is all state dollars. There is not really any discussion going on to talk about the overlap.” -ACS Focus Group Participant

For mental health providers, the issues largely center on the impression that mental health services are being used unnecessarily or in place of other supports such as behavioral services and the experience that individuals with IDD often get “stuck” in a mental health services that are not appropriate to meet their needs.

One emergency department psychiatrist who participated in a focus group summarizes his observations and impressions of this challenge:

“The perspective of the people coming to the ED, whether it’s a family or residential staff, is that they think they are having an emergency for whatever reason. From their perspective, they are in crisis of some kind and don’t know what to do. What equals a crisis in a group home or for a family doesn’t necessarily equal what an ED doctor would say is a crisis requiring hospitalization. For you it’s an emergency but not for the ED. The question is how to acknowledge their distress and come up with alternatives to going to the ED.”

IDD providers and families report a great deal of reluctance on the part of mental health providers to accept individuals with IDD into services. They express concern that mental health symptoms are often overlooked or under-diagnosed because the person has IDD and symptoms are seen as simply behavioral in nature.

“The doctor sees the DD and assumes there couldn’t possibly be a psychiatric reason. We’re told, ‘It’s a behavior problem so take him home.’” -IDD Provider Focus Group Participant

The lack of a clear role for providers makes it difficult for families to navigate the system successfully. 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.



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While the majority of family members surveyed feel encouraged by providers to take an active role in their family member’s treatment (61%), only 11% report that care providers always respond to their wishes. Only 16% of family members feel that providers always take their opinions into account. In addition, only 21% of families feel that they are getting all of the information or collaboration they need and desire. The table below shows how family members who participated in telephonic surveys feel about the responsiveness of the system to the needs of their family member.

Table 4: 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?	11%	11%	17%	61%	3%
How involved were you in treatment?	11%	11%	21%	58%	5%
Did services respond to wishes of family?	17%	17%	56%	11%	0%
How much say did you have in outpatient services?	11%	5%	47%	37%	0%
How satisfied were you with your role in treatment?	5%	0%	32%	63%	0%
How much did providers respond to your concerns?	16%	5%	47%	32%	0%
How much did providers take into account your opinions?	5%	16%	63%	16%	0%
Did providers recognize burdens on families?	22%	17%	17%	44%	0%
How much information did you receive about illness?	16%	16%	42%	21%	5%

Family members interviewed state that they want to have a greater voice in the service planning process because they know what their family members need. When asked what advice they would give to



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service planners, **65% of the families interviewed want the provision of services to consider the needs of their family members based on their IDD and mental health needs.** Most family members interviewed cite a lack of training about IDD by mental health providers and poor coordination between the two systems as gaps in effective service delivery.

“(Families) need better ways to navigate the system, get access to professionals who specialize in IDD, more training for staff” -Parent of an individual with IDD

“Never forget the family situation. If you keep this in mind, you can arrange any planning for families. If there is a great social skills group somewhere but I can't get to it or pay for it, it doesn't matter. Personalize coordination of services based on each family situation. Think, "how can you make the game happen" based on the needs of each family (how many other kids? do they have disabilities? where can you leave them when your one child gets services?)’ -Parent of an individual with IDD

Theme 2: There is a need to Increase Capacity to Effectively Intervene in Crisis Situations

The next theme to emerge from the analysis is the need to increase capacity within NYC to effectively help individuals experiencing a crisis. The primarily reported issues in examining crisis services include: an overall lack of capacity within the system and a lack of appropriate training and expertise in the mental health system on how to effectively treat individuals with IDD when they do access services. Once again, there are significant differences in the responses of the providers within the mental health and IDD communities. IDD providers list crisis services as the biggest gap in the system. They overwhelmingly express a concern that individuals with IDD are excluded from mental health services or only given minimal treatment. The data also shows that IDD providers and family members rate access and helpfulness of crisis services more similarly.

“The hospital will admit someone for psychiatric care only if they are threatening to hurt themselves or someone else. So when things get bad, they can go on for years at home suffering and not get their medicine adjusted, which should be done where they can be observed over time. And if the person is admitted, they are sent home before they are really better.” -IDD Provider Focus Group Participant

MH providers report a lack of willingness to accept individuals with IDD into services because the individuals can be viewed as difficult to work with, disruptive to the milieu, or unable to meaningfully participate in services. They also express a concern that individuals with IDD will have long in-patient stays beyond what they consider necessary. They point to the need for a stronger coordination of services before, during and following an in-patient hospitalization.



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This population needs one to one staffing, which we can't provide. Our only solution is to keep them isolated from the rest of the population in a back bedroom, but then the family complains that they are not getting the same treatment as everyone else. —Hospital Provider Focus Group Participant

The online survey listed 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 available by 27% of respondents. However, families rate these services as appropriate and helpful only about 15% of the time. Nearly half of the people who reported that they gained access to crisis services in the past did not find the service helpful. Also, 26% of respondents reported that they did not have enough information about crisis services at the time to answer this question. **This suggests that New York City citizens may not have information on who to call or where to go in times of crisis.**

According to the on-line survey, mental health providers are the least likely to have information about crisis services. 44% of mental health providers responded "don't know" compared with 31% of families and 21% of ID/DD providers. Mental health providers are more likely to know about in-patient psychiatric bed availability and crisis stabilization services and less likely to know about community crisis bed availability or hospital diversion services.

An even greater difference between the perspectives of mental health, IDD providers and family members can be seen from their respective responses to the availability of crisis services in their area. Approximately 50% of mental health providers feel that crisis services are available compared with less than 25% of IDD providers and 21% of family members.

Table 5: 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	63.6%	22.5%	7.1%
Crisis Stabilization/Hospital Diversion	50.0%	21.1%	21.4%
Out-of-Home Crisis Respite Services	36.4%	22.7%	20.0%
Community-Based Psychiatric Inpatient Beds	58.3%	29.6%	28.6%
Crisis Intervention Services	50.0%	22.9%	28.6%



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According to the on-line survey responses, there is very little difference between families and IDD providers with regard to their perceptions of crisis capacity within the system. The biggest difference between the two groups is in the area of mobile crisis, in which families were more than 15% less likely to report that service capacity exists than IDD providers. Comments from families regarding mobile crisis issues relate to long wait times, lack of after-hours response and services not truly being crisis oriented.

“For years, I have gotten a yearly flyer about the "Mobile Crisis Service", but when actually called, we are usually told to bring the child to ER or call 911.” - Parent Respondent

“There is nothing. The mobile crisis service will come to a family only if the person is both refusing to take medicine and is not receiving any treatment (psychiatrist/therapist). And if they did agree to come, it wouldn't be immediately, but in a few days or so. So it's not for crises.” - Parent Respondent

The table below represents the distribution of crisis service feedback by borough and indicates that Brooklyn and Queens have more resources for crisis intervention and that individuals in Queens and Staten Island have the highest perceived availability of crisis services overall.

Table 6: Availability of Service by Borough

Availability of Service (% all or some of what is needed)						
	Mobile Crisis	Crisis Stabilization	Crisis Respite	In-Patient Psychiatric Beds	Crisis Intervention	Overall Crisis Services
Manhattan	22.2%	27.8%	23.5%	16.7%	22.2%	22.5%
The Bronx	23.5%	29.4%	33.3%	29.4%	11.8%	25.5%
Brooklyn	26.7%	16.7%	20.0%	33.3%	40.0%	27.3%
Queens	22.7%	22.7%	36.4%	47.6%	38.1%	33.5%
Staten Island	41.7%	25.0%	36.4%	33.3%	9.1%	29.1%

When asked whether or not the services available to them are helpful, there are significant differences in the responses from mental health providers and both IDD providers and family members. Mental health providers are the most likely to feel that crisis services are available, but when asked about the helpfulness of those services, their overall perception decreases by an average of 10%. **This is significant, because it supports the idea that mental health providers may not feel that individuals with IDD can benefit from mental health services.**

Families are not satisfied with the availability of crisis services and often do not know if they exist. On-line surveys and phone interviews drew similar responses from family members. According to the information gathered through phone interviews, the majority of families (64%) feel that there are little or no options for crisis services outside of the hospital and 100% of the families with an opinion on in-



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patient services report that when these services have been utilized in the past they have not been helpful. Overall, respondents rarely rated, “do not know” except when asked about crisis options outside the hospital (26%) and the availability of crisis help on weekends and in the evenings (17%).

This suggests that many families may not be aware of the services that are available to them, or have not gained access when the services have been needed.

Table 7: 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?	53%	11%	5%	5%	26%
Were inpatient services helpful?	67%	0%	0%	0%	33%
How much information did you receive about what to do in a crisis?	6%	17%	44%	33%	0%
How much information did you get about whom to call in a crisis?	21%	16%	32%	32%	0%
How much crisis help was available nights or weekends?	44%	17%	11%	11%	17%

Theme 3: Increase access to expertise and training to develop expertise across New York City

Along with the need for crisis services and improved overall availability of mental health services is the need for ongoing training and access to expertise within NYC to better support people with IDD and behavioral health service needs. IDD provider and family focus groups most frequently cite the need for improved training as an issue. 65% of Survey respondents and family interview participants cite a lack of providers available who are trained to effectively support individuals with IDD and co-occurring mental health conditions as a major barrier in the system.

“Some of the DD individuals end up in the MH system but the staff is unable to provide necessary supports due to lack of training.” -On-Line Survey Respondent

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



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- 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?

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). Unlike responses about crisis services, the questions related to training had less than 10% of respondents who answered “don’t know”. This rate was consistent between the three primary groups of respondents (MH providers, IDD providers and family members) as well as between boroughs suggesting that all groups feel they had enough information about available training to respond.

Results show that just over half (59%) of stakeholders report that IDD-trained mental health professionals are available and 54% believe the options available match their needs. As displayed in Table 5 below, there are very large differences among the groups with the vast majority of MH providers feeling that training is both available (83%) and helpful (91%), while only 29% of families and 45% of IDD providers feel that the training is helpful. **Family member respondents are least likely to see training as available and appropriate based on their direct service experiences and outcomes, and this is consistent across all respondents in NYC. One mental health provider clearly articulated a theme identified in the focus group that she, in fact, feels unprepared to work with individuals with IDD since she did not receive formal training.**

“I feel that in my initial training, there was little emphasis placed on helping individuals with developmental disabilities. My training was mostly on-the-job training.” -Mental Health Provider

Table 8: Staff Training by Respondent

Group Responding	Staff Training (% all or some of needed)		
	Available	Matched Needs	Helped
MH Providers	83.3%	83.3%	91.7%
ID/DD Providers	58.7%	52.0%	45.2%
Family members	41.2%	35.3%	29.4%
Overall	58.6%	53.9%	50.0%



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Trends also indicate a variation in perceptions of training availability and helpfulness across NYC boroughs. While only 44% of respondents from Manhattan find that training is available, those who have accessed training also report that it helpful. Individuals from the Bronx and Staten Island have the highest percentage of respondents who feel that training is available, but also have the biggest differences among subgroups when asked if the available training is helpful. **Overall, this information suggests that when stakeholders know how to access training, they tend to report that it is helpful. This means that any standardized evidence-based training offered through the NYCSTART Program will likely be viewed as helpful and informative.**

Table 9: Staff Training Availability and Helpfulness by Borough

Staff Training (% all or some)					
	Manhattan	The Bronx	Brooklyn	Queens	Staten Island
Available	44.4%	66.7%	55.6%	62.5%	69.2%
Helpful	44.4%	41.2%	51.5%	58.3%	53.8%
Variance	0.0%	25.5%	4.0%	4.2%	15.4%

Tables 10 through 13, which can be found below, graphically demonstrate the respondents' perceptions related to the availability and helpfulness of consultation. Service consultation is rated the least available and helpful, while results for clinical consultation are quite similar to the ratings for training overall. The consultation trends identified between respondent groups is very similar to other responses where mental health providers are much more likely than IDD providers and family members to report that consultation is both available and helpful.

There are larger differences in the perception of clinical consultation across boroughs with Manhattan having the lowest perceived availability. People responding to the survey in Queens reported the highest rate of availability (79%).

When asked to rate the availability of consultation services, respondents answered "don't know" nearly 20% of the time. When taking the responses from family members in isolation, this number is significantly higher (46%). **This indicates that family members have concerns that professionals who are providing services are not trained adequately or supported enough in order to be providing effective services. Family members completing the survey also cite the need for cross training between systems as a major issue.**



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“When my daughter with Autism was in psych hospitals, we had to make our own arrangements to bring in consultants knowledgeable about IDD. What happens to families who do not have our resources? Even our efforts were of minimal benefit when dealing with hospital employees clueless about people with IDD” - Parent Respondent

Table 10: Service Consultation by Respondent

Group Responding	Service Consultation (% all or some)		
	Available	Matched Needs	Helped
MH Providers	81.8%	90.0%	80.0%
ID/DD Providers	35.2%	34.3%	35.2%
Family members	20.0%	20.0%	20.0%
Overall	39.3%	38.5%	37.7%

Table 11: Service Consultation Availability and Helpfulness by Borough

	Service Consultation (% all or some)				
	Manhattan	The Bronx	Brooklyn	Queens	Staten Island
Available	23.5%	41.2%	40.0%	39.1%	61.5%
Helpful	23.5%	35.3%	44.8%	34.8%	53.8%
Variance	0.0%	5.9%	-4.8%	4.3%	7.7%



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Table 12: Clinical Consultation by Respondent

Group Responding	Clinical Consultation (% all or some)		
	Available	Matched Needs	Helped
MH Providers	83.3%	81.8%	90.9%
ID/DD Providers	66.2%	60.8%	62.2%
Family members	37.5%	31.3%	37.5%
Overall	61.6%	56.4%	59.5%

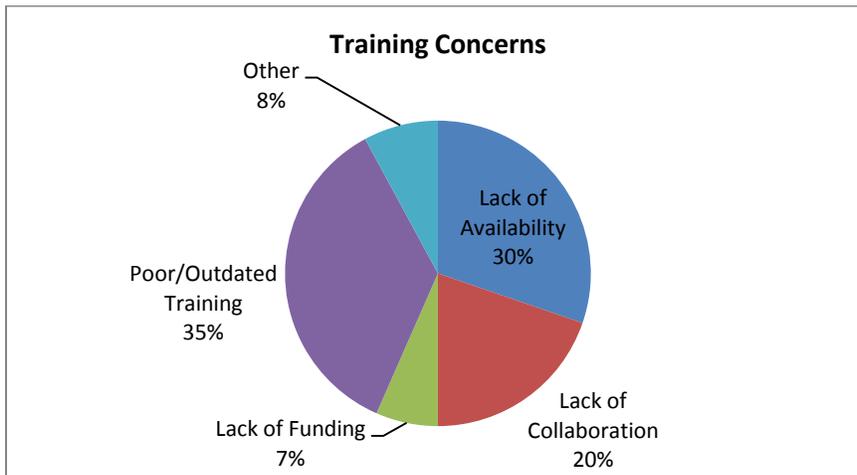
Table 13: Clinical Consultation Availability and Helpfulness by Borough

	Clinical Consultation (% all or some)				
	Manhattan	The Bronx	Brooklyn	Queens	Staten Island
Available	33.3%	58.8%	66.7%	79.2%	61.5%
Helpful	33.3%	58.8%	59.4%	79.2%	61.5%
Variance	0.0%	0.0%	7.3%	0.0%	0.0%

All survey respondents who rated a service area as ‘None’ or ‘Very Little’ were asked to provide an explanation for that response. These responses help to identify the perceived gaps in training across NYC. Figure 6 outlines survey respondent training concerns. **A review of these concerns reveals that 65% of individuals completing the survey report that training is simply not available or is poor and/or outdated.** The second most reported training concern is a lack of availability (30%). Lastly, 20% of respondents report that the lack of collaboration across systems is prevalent. This is also a trend that has identified through focus group discussions.

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



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

Lack of Knowledge (35%):

- “There are very limited services for people experiencing behavioral and psychiatric crises. There are few psychiatrists who specialize in this population. There are no real supports for families experiencing behavioral crises that cannot safely manage their family member at home.” -On-Line Survey Respondent
- “Some may have tried to help but really do not have training or experience with teens with Autism entering the difficult time of adolescence.” -On-Line Survey Respondent
- “Sometimes staff in the field doesn’t have experience working with the population. People’s background should guarantee some empathy and understanding of disability. Staff needs to know about Autism, what is a psychotropic medication, what is mental health, what is a psychiatric feature, does a behavior need to be changed?” -On-Line Survey Respondent

Availability (30%):

- “There are not enough services available for people who are dually diagnosed with IDD and psychiatric disabilities. Neither OPWDD nor OMH is able to successfully serve these individuals.” -On-Line Survey Respondent
- “There are very few options for people who have coexisting mental health conditions in addition to IDD. It is often challenging to find the proper supports and services for people who have these and behavioral challenges. “ -On-Line Survey Respondent



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Lack of Collaboration (20%):

- “They appear to function as two different entities who do not communicate with each other outside of referring someone to the other's program.” -On-Line Survey Respondent
- “Once again, there is very little connection between mental health and IDD services. We are often left having to address one need over the other.” -On-Line Survey Respondent
- “There is no overlapping of support from IDD to MH” -On-Line Survey Respondent

The lack training available that focuses on IDD and co-occurring mental health conditions has emerged as the primary concern for families and service users/self-advocates accessing the system. **This 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.**

“Beds may exist, but without doctors/staff trained in working with people with IDD this is not adequate.” -On-Line Survey Respondent

Respondents were asked whether family education services are available and helpful. About 50% of IDD and mental health providers perceive family education services as being available and helpful while only 20% and 25% of family members, respectively, report the perception of availability and helpfulness. **This is a significant finding, since it suggests that providers across systems may feel that families have more knowledge and information than they actually have about what constitutes a crisis and where to go for help.**

Table 14: Family education by Respondent

Group Responding	Family Education (% all or some)		
	Available	Matched Needs	Helped
MH Providers	50.0%	41.7%	50.0%
ID/DD Providers	52.8%	45.8%	41.7%
Family members	20.0%	26.7%	25.0%
Overall	45.9%	40.4%	38.2%



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- “Many families of people with IDD are not given enough education about possible mental health concerns that may be co-occurring.” -On-Line Survey Respondent
- “No one has ever advised me about this but instead I have experienced lack of comprehension and anxiety from DD providers regarding symptoms. They would just say to go to the emergency room in times of crisis. Ongoing symptoms are met with total lack of education and lack of interest.” -On-Line Survey Respondent
- “Too many people don’t know who to ask, where to go, and how to start” -On-Line Survey Respondent

Theme 4: There is a need to increase family awareness of and 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 60% of respondents rating them as always or somewhat available.

Article 16 clinics and therapy services within IDD provider agencies are mentioned by both MH and IDD providers as assisting in this area. This finding is supported by the claims data that shows that the majority of Medicaid mental health expenditures, over \$55 million annually, were spent on outpatient mental health clinic services.

One of the most critical findings to emerge is the existence of a significant gap between provider and family perceptions about service availability. The biggest variance is for outpatient therapy in which over 66% of providers feel the service is available compared to just 20% of families. **This suggests that the experiences of family caregivers do not match the perceptions of providers of these services with regard to access and this may lead to greater use of emergency services such as mobile crisis teams, emergency departments and police. Families cite long waiting lists as a major issue in accessing even those services that are available to them.**



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Families report that they do not have as much choice as they would like in mental health service providers. In general, less than half of the families interviewed (47%) feel that the services available are always the ones they need. 75% indicate that they are not given the option to choose between services and service providers they prefer and that the services that are available are not always convenient and easy to access.

Table 15: Service Accessibility

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?	21%	5%	26%	47%	3%
Was there opportunity to choose mental health services?	40%	20%	15%	25%	3%
Was their opportunity to choose provider?	37%	11%	37%	11%	5%
How convenient were services?	11%	53%	26%	11%	0%
Were services flexible enough to meet needs?	11%	11%	42%	37%	0%
How satisfied were you with outpatient services?	11%	26%	32%	32%	0%

“Never forget the family situation. If you keep this in mind, you can arrange any planning for families. If there is a great social skills group somewhere but I can’t get to it or pay for it, it doesn't matter. Personalize coordination of services based on each family situation; think ‘how can you make the game happen’ based on the needs of each family -how many other kids? do they have disabilities? Where can you leave them when your one child gets services?” -Parent of an individual with IDD

Survey questions eliciting information from family members regarding availability and choice for outpatient psychiatry show similar trends as demonstrated throughout this report. Providers are 30% 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, the 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. IDD providers and families are 15% less likely than mental health providers to view psychiatry services as helpful when available to them. They again cite long waiting lists and poor training on issues related to IDD for mental health professionals as the primary concerns.



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- “Long wait lists to see psychiatry in an IDD clinic.” -On-Line Survey Respondent
- “Few clinics specializing in IDD communities, ones that do exist are backed up and do not have well-trained staff.” -On-Line Survey Respondent
- “I know of only one psychiatrist who has knowledge of IDD. I would not know where to find another who would have enough knowledge of both IDD and psychiatric disorders.” -On-Line Survey Respondent

Other Findings

Overall, IDD services are perceived to be more available than mental health services by people completing the surveys. Only an average of 26% of respondents surveyed feel that little or no IDD services exist (or need to be developed) as compared to responses to similar questions measuring the perception of availability of mental health services (60% of respondents perceive that little to no MH services exist). Other significant findings include the improvement of crisis services as the greatest need (52%) followed by the need for improved employment opportunities for individuals with IDD (48%). Respondents also highlight the need for behavioral supports and community respite to be more readily available to individuals and families who are accessing IDD and mental health services.

When asked about the effectiveness of IDD services in the community, responses among groups were fairly consistent. About 26% of all respondents are completely satisfied with services (the services work well), while the majority (47%) feel that they need improvement (could be strengthened). Slightly more than ¼ of the respondents (27%) reporting that there is a lack of needed services in the community.

The services in which the highest percent of individuals indicate that they work well are service coordination (40%), residential supports (39%) and day habilitation (39%). 37% of respondents also rate Article 16 clinical services as working well. This outcome is consistent among family members interviewed and focus group participants that indicate these services as being effective when available. **While service coordination, residential supports and day habilitation are rated the highest with regard to satisfaction, it is significant to note that more than half of all respondents report dissatisfaction with effectiveness of these services for this population. These findings may indicate that, from the viewpoint of the responders, the system as a whole is underperforming with this population and more training and support through the NYSTART program may be helpful.**

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 crisis services



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(52%), employment services (47%), respite (41%), behavioral supports (35%) and transportation resources (30%) as being the highest need area of development.

Table 16: IDD Services

IDD Service	Works well	Works, but could be strengthened	Needs to be developed
Facility-Based Residential Services-ICF/DD	35.45%	49.09%	15.45%
Residential Supports-Supportive apartments (less than 24 hour)	38.60%	40.35%	21.05%
Residential Supports-Home and Community-based Supports	28.07%	49.12%	22.81%
Community Habilitation, Respite	29.41%	55.46%	15.13%
Day Habilitation Services	39.32%	48.72%	11.97%
Supportive Employment (SEMP)	26.50%	52.99%	20.51%
Employment Opportunities	6.78%	45.76%	47.46%
Facility-Based Residential Services-Developmental Centers	18.09%	45.74%	36.17%
Residential Supports-Individualized Residential Alternatives (IRA)	39.50%	41.18%	19.33%
Residential Supports-Supervised apartments (24 hour)	38.39%	34.82%	26.79%
Transportation Services	15.93%	53.98%	30.09%
Self-Direction	13.76%	54.13%	32.11%
ID/DD Service Coordination	40.17%	45.30%	14.53%
Medical Services	35.65%	49.57%	14.78%
Clinical Services (Article 16)	37.50%	49.11%	13.39%
Crisis/Emergency Services	13.91%	33.91%	52.17%
IDD Behavioral Supports	18.26%	46.96%	34.78%
Family respite-In-Home Respite	20.87%	48.70%	30.43%
Family respite-Facility-based (weekend/vacation)	16.22%	43.24%	40.54%
Special Education	20.91%	60.91%	18.18%
Other Therapies (music, recreation)	17.70%	39.82%	42.48%
School-based Supportive Therapies	19.81%	50.94%	29.25%
Early Intervention Services	27.88%	50.96%	21.15%

The survey recipients responses to the effectiveness of IDD services supports outcomes that are reflected in other areas of the analysis: **The need to improve capacity of the system overall through accessible and effective training, consultation, and technical support for providers and families and individuals with IDD and co-occurring mental health conditions.**



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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 only crisis response services is not the answer. Rather, the improvement of crisis services in addition to the development of supports that promote independence and quality of life (e.g., vocational services, recreational opportunities) are necessary. This suggestion is supported by research that indicates that the quality of an individual's life contributes to his/her mental health.



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Recommendations/Next steps

Following are recommendations based on the analysis of services in New York City:

The START model is an excellent fit based on the findings from the analysis just conducted. Modifications of the model will be to emphasize network development more proactively than has occurred in the NYSTART Regions 1 and 3 pilots to date. While both Region 1 and Region 3 have worked on developing and enhancing networks, this will require greater focused attention from the onset as NYC services are developed. It is important to ensure that the MH and IDD providers, along with other stakeholders, take equal ownership of the model and the resources that will be put in place. The lack of clarity with regard to the role of mental health services in supporting people with IDD and behavioral health needs suggests that this needs to be a focus from the first stages of planning. As a result we recommend that assessment teams be established as part of this process (see below).

The findings from CETs indicated that attention to quality of life and history of clinical and life experiences is often overlooked when someone is experiencing difficulties, but are key to long term and effective remedies and to allowing the individual to gain the most from what is being offered to him or her. The methods employed by START include comprehensive assessment, evidence based positive psychology, and strength based approaches and may help to address this issue. It is also indicative that services to promote independence and life satisfaction including work support and health promotion will be key in the service system going forward. In addition, direct support providers may benefit from the outreach, training and coaching that will be available through their local NYSTART teams.

Recommendations:

The START model can help to address 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 NYC:

1. Finalize the design of the START programs (specific recommendations are in the addendum to this report). In the request for proposals to provide NYCSTART services, emphasis should be placed on the fact that NYSTART is aimed to establish an integrated behavioral health network that includes both IDD and MH providers.
2. The NYCSTART Program should be operated by mental health providers who have expertise in IDD. It is important that the services not be isolated as part of the IDD system alone.
3. The development of a plan by the NYCSTART 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 NYC, however, existing relationships will be important to begin the process.



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4. Development and implementation of the interdisciplinary professional learning community across NYC and linked with other NYSTART programs across the state 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 this as accessible to many as possible.
5. NYCSTART programs must work closely and collaboratively with all first responders already established in NYC 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. NYCSTART programs should work to establish regional multi-modal consultation teams to assist with assessment of individuals with more complex needs. This consultation team should be comprised of the START Clinical Director, START Medical Director, a neurologist, primary care physician, an occupational therapist and other specialists as needed. One team should specialize and be dedicated to consulting with teams serving children and the other adults. To maximize resources, NYCSTART teams may share resources as possible to implement these teams. It is highly recommended that they be provided in a Medical School setting. Providers submitting proposals should include their plan for addressing this, including costs and plans to bill for this service.
7. NYCSTART 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. NYCSTART 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, NYCSTART 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 NYCSTART 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



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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. NYCSTART advisory councils should be formed to help with this process. The proposed provider should have a plan to assure that this occurs.

11. Publication and information about existing services and how to access them can be provided through the NYS OPWDD website and other communication mechanisms. All service providers need to know what is available and accessible as well as how to assist families and service users in getting needed resources and supports.
12. The NYCSTART teams need to develop a plan as to how they will interface with schools and schools systems. The proposed provider should have a plan to make this happen. 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 pay close attention to what we learn from data collection and analysis of the needs of this population overtime. The advisory councils developed to help oversee NYSTART programs should pay close attention to this information over time.

Recommended program design for NYCSTART

Estimated team sizes are based on population density, the number of people in the OPWDD system and prior experience with START programs. However, given the size and scope of the teams proposed, it is recommended that they be developed in stages beginning with clinical teams with a minimum number of START coordinators per team to be determined by the state, adding coordinators over a 24 month period as the program becomes fully operational. In addition, the resource center site should be identified early on in the process. While Resource Center services are not typically underway until the Clinical team is fully operational, the time it takes to develop and implement the program requires early identification of the site. Therefore this should be required as part of the RFP process.

Team 1 Brooklyn/Staten Island (first to go due to facility closing)

- 1 FTE Director
- 1 FTE Assistant Director
- 1 FTE admin assistant
- 1 FTE Clinical Director
- .50 FTE Medical Director (may be more than one person)
- 1FTE Resource Center Director
- 1 FTE in Home supports Director

Brooklyn: locations should be recommended by the provider

- A. 1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant
- B. 1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant



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C. 1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant

Staten Island: One team centrally located

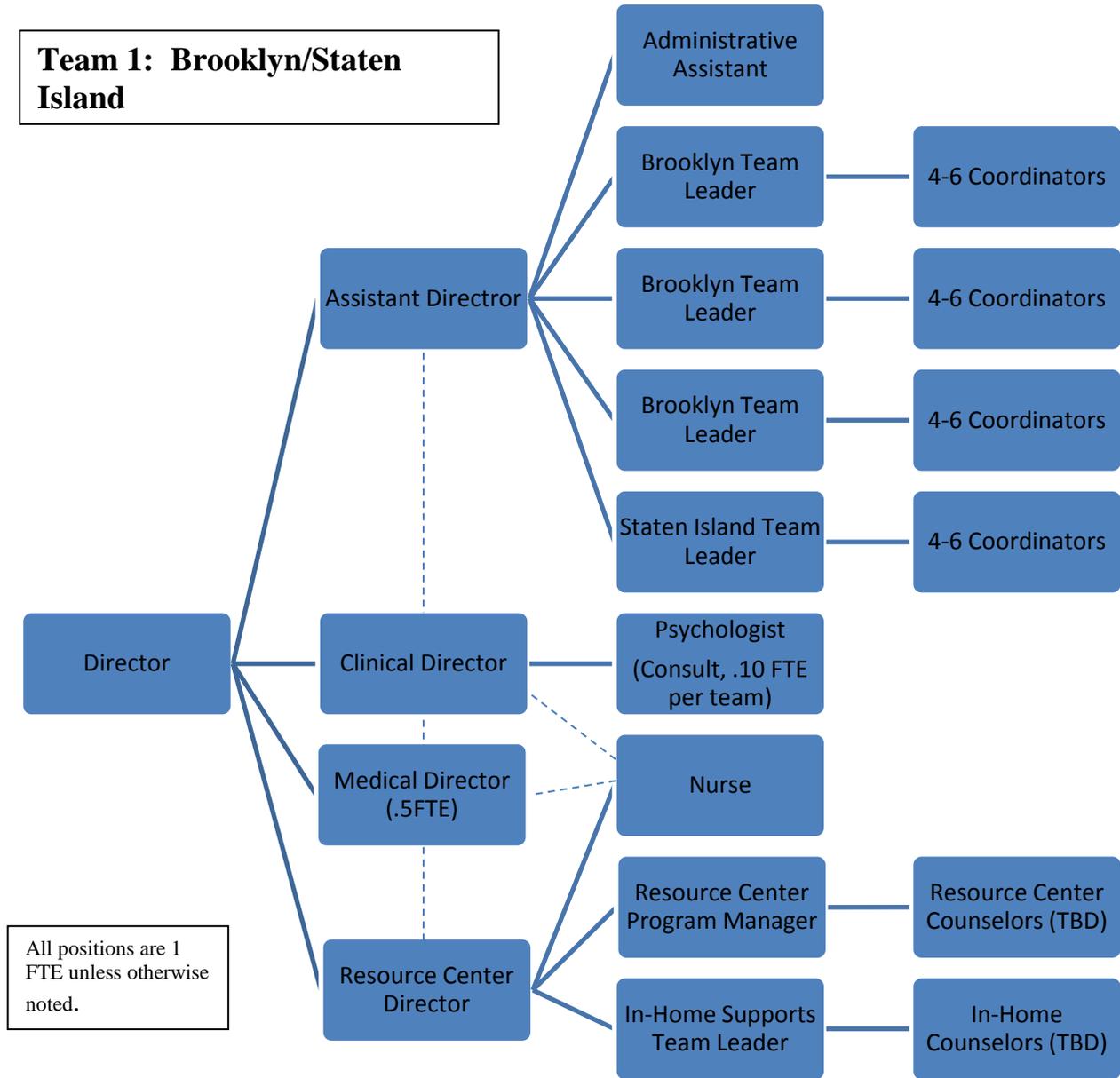
1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant

Interdisciplinary consult teams meet monthly (one child team, one adult team)



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Team 1: Brooklyn/Staten Island



All positions are 1 FTE unless otherwise noted.



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Team 2: Manhattan, Bronx, Queens (90 days after Team 1)

- 1 FTE Director
- 1 FTE Assistant Director
- 1 FTE admin assistant
- 1 FTE Clinical Director
- .50 FTE Medical Director (may be more than one person)
- 1 FTE Resource Center Director (per center may need two)
- 1 FTE in home supports director
- Interdisciplinary consult teams meet monthly (one child team, one adult team)

Manhattan

Two sub groups

- A. Lower Manhattan (1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant,)
- B. Upper Manhattan (1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant)

Bronx : One team centrally located

1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant

Queens: 2 sub-groups

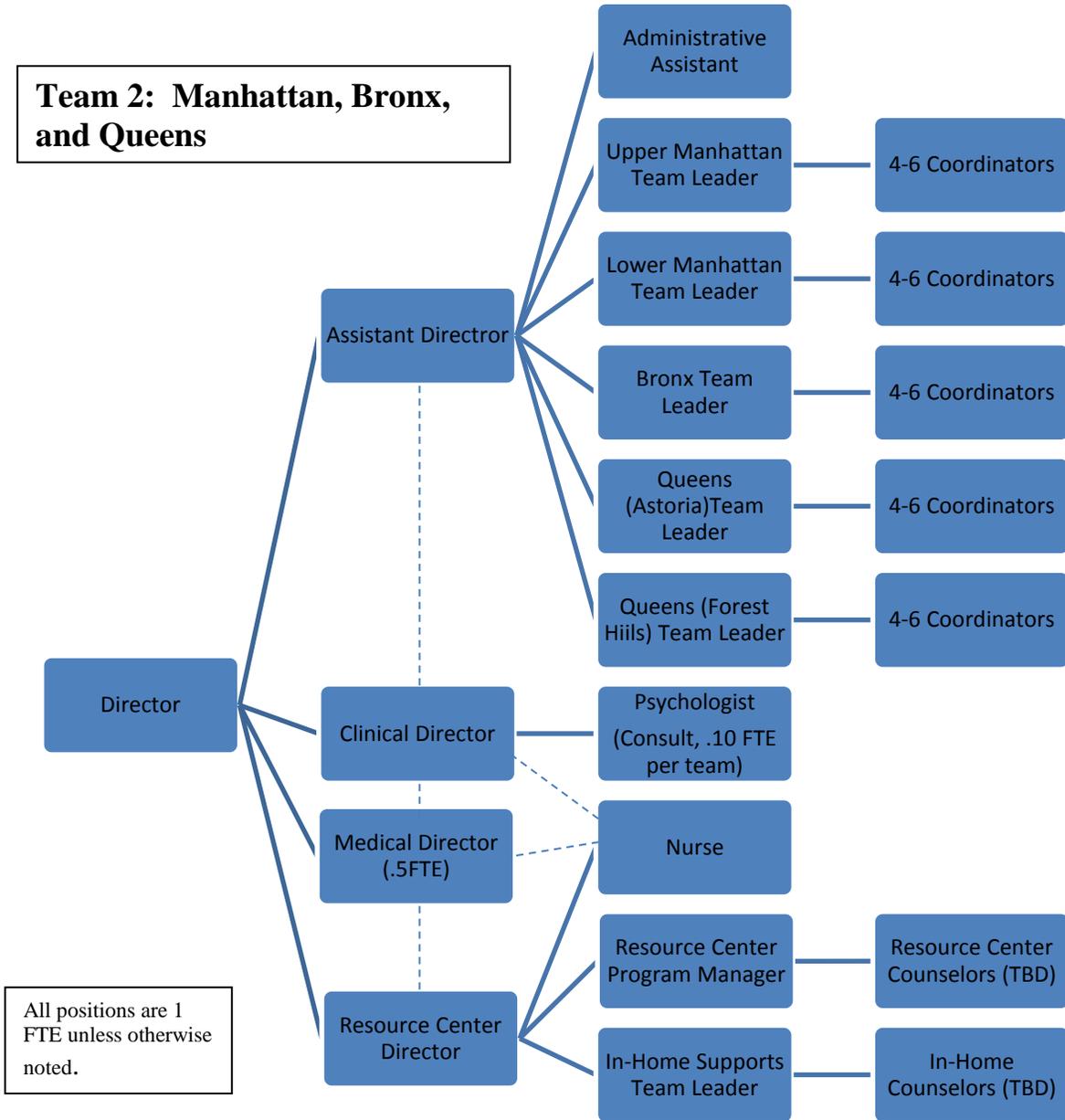
- A. Astoria/LI City to Forrest Hills (West) (1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant)
- B. Forrest Hills to LI (East) (1FTE team lead, 4-6 FTE coordinators, 4 hours a week Psychology consultant)

These recommendations are based on the size and population density and diversity of each borough.



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Team 2: Manhattan, Bronx, and Queens



All positions are 1 FTE unless otherwise noted.



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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



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Appendix B: New York City IDD/MH Task Force Members

Abraham Taub, Maimonides Medical Center	Brooklyn
Alan Galanga, OPWDD	
Al Pfadt, Independent Consultant	All Boroughs
Amy Anneling, OPWDD	
Celia Blackman, Bronx Family Support Advisory Council	Bronx
Cliff Datys, Administration for Children's Services, Parent	All Boroughs
David Roper, Rose F. Kennedy Center	Bronx
Dawn White, Heartshare Human Services of NY	Brooklyn, Queens, Staten Island
Debra Greif, Brooklyn Family Support Advisory Council	Brooklyn
Donna Limiti, OPWDD	
Angie Francis, OPWDD	
Ellen Bleckman, OPWDD	Manhattan
Elizabeth Cambra, OPWDD	
Elizabeth Lonegran, OPWDD	Bronx
Gerald Cohen, NYC Dept. of Health & Mental Hygiene	All Boroughs
Hindy Hecht, Bais Ezra-Ohel Family Services	Brooklyn, Queens, Manhattan, SI
Irene Cavanagh, Eden II	Staten Island, Brooklyn
Ivy Butler, OPWDD	Staten Island
Janet Strauss, OPWDD	Brooklyn
Janice Chisolm, NYC Dept. of Health & Mental Hygiene	All Boroughs
Janyce Jones, OMH- Bronx Borough Coordinator	All Boroughs
Joanne Siegel, Rose F. Kennedy Center	Bronx
John Thopson, PSCH, Inc.	Queens, Staten Island
Kathleen Nowak, On Your Mark, Parent	Staten Island
Kevin Meade, Community resource, Family Member	Bronx
Linda Blumkin, Parent	Manhattan
Lisa Steinhouse, NYC Department of Health & Mental Hygiene	Brooklyn, Queens, Manhattan, SI
Liz Devoti, SI Family Support Advisory Council, Dept. of Educ.	Staten Island
Lynn Decker, Self-Direction Broker, Parent	Manhattan, Brooklyn
Paul Cassone, Guild for Exc. Children, DD Council for Bklyn.	Brooklyn
Marisa Derman, NYC OMH Field Office	All Boroughs
Marylee Burns, NYC Heartland Hospitals Corp.	
Nobella Parham, Institute for Community Living	Manhattan, Brooklyn, Bronx
Priscilla Fuller, Services for the Underserved	Brooklyn, Queens, Manhattan, SI
Rachel Lewitter, Bais Ezra-Ohel Family Services	Brooklyn, Queens, Manhattan, SI
Raymond Denatale, Independent Residences	Queens, Brooklyn, Manhattan, Bronx
Shana Gandall, Rose F. Kennedy Center	Bronx
Sheila Gholson, OPWDD	
Simone Chung, PSCH, Inc.	Queens, Brooklyn



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Sonji Phillips, Unique People Services

Spencer Fales, Independent Living Association

Tasnim Rashid, Institute for Community Living

Ted Kastner, Rose F. Kennedy Center

Terence Blackwell, Services for the Underserved

Terry Slavens, Richard Hungerford School

Tina Veale, Bronx Family Support Advisory Council

Tzivy Reiter, Bais Ezra-Ohel Family Services

Wendy Colonna, OPWDD

Bronx, Queens

Brooklyn, Staten Island, Manhattan

Bronx, Manhattan

All Boroughs

Staten Island

Bronx

Brooklyn, Queens, Manhattan, SI



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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
November 4, 2014	IDD Clinic Providers	22
November 5, 2014	IDD providers (residential, MSC)	22
January 8, 2015	Mental Health Providers	7
January 8, 2015	Hospital Providers-Group 1	12
January 8, 2015	Hospital Providers-Group 2	13
January 9, 2015	IDD Providers (Day Services)	25
January 9, 2015	Families	14
January 9, 2015	Self-Advocates	5
February 12, 2015	Administration for Children's Services	5



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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 in each of the 5 boroughs of New York City. 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 (or projected number if yet to occur)
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
Bronx	June 3, 2015	Unique People Services	Prader Willi Syndrome and Treatment Considerations	50