



Annual Monitoring Report And Data Summary

October 1, 2011 – September 30, 2012

EXECUTIVE SUMMARY

2012 was another year of change in the provision of services and supports to people with intellectual and other developmental disabilities in the District of Columbia. After years of effort, data now suggests that progress is being made, and services are generally improving. It will require additional time to tell whether these results indicate an emerging system of reliable services. The answer to this question should become clearer over the next year as testing through different types of monitoring will be on-going. A couple encouraging signs are:

- 79% of the people we met lived in non-institutional settings.
- Institutional placements continue to decline, though the pace has slowed
- 96% of the people we met indicated that they like the home in which they live

Notable progress was made in the long standing class action litigation brought against the District in 1978. Three of the nine outstanding areas in the *Evans* federal court case were certified as in compliance. Monitoring in those areas for class members is now the responsibility of Quality Trust. 2013 will be a pivotal year in this case. Expectations are high that at least parts of the remaining six areas will be vacated by the Court and that the plans needed to close those areas completely will be operational and in place. The District's renewal application for the Home and Community Based Services Medicaid waiver for people with intellectual and other developmental disabilities was approved in November 2012. Also, a new rate methodology for reimbursements of Medicaid dollars to providers of Intermediate Care Facilities for people with Intellectual and other Developmental Disabilities (ICF/IDDs) was developed, but has yet to be implemented. These are important steps needed to strengthen the service system, and continue support for ongoing reforms.

At the same time, there continue to be areas within the service delivery system which need more development. In Our Report issued in 2010 we noted that "Removal of providers who cannot demonstrate consistently acceptable practice must be the shared outcome of government agencies"¹. Ultimately, quality in services is dependent on the people delivering the services. Quality requires the delivery of multi-dimensional services to a diverse group of people with individually unique needs. While overall data indicates that services are improving, we continue to find instances where services provided reflect low expectations of and for people with developmental disabilities. This is evidenced to us when we observe the following:

- 46% of the people we met have friends without disabilities
- Identified concerns with practices related to developing, approving and implementing Behavior Support Plans

What people with disabilities need and want most are ordinary human outcomes: to be active, to work and earn money, to be free to develop in healthy and meaningful ways. For that to happen, those who spend the most time with them need to be their ally and believe in their potential. Service improvement initiatives currently underway that are designed to increase expectations and promote change in the quality of individual support provided to each person are crucial for building the strong systems needed to effectively assist people with disabilities.

¹ QUALITY TRUST, Annual Monitoring Report & Data Summary, at 19 (October 1, 2009 – September 30, 2010), available at <https://www.dcqualitytrust.org/documents/QT2010MonitoringReport.pdf>.

INTRODUCTION

This report combines data from a number of sources, and our opinions about certain issues based on our ten years of meeting and advocating for people in the District of Columbia. Positive trends noted over the past two years have continued. 2012 was another year of change in the provision of District-funded services and supports to people with intellectual and other developmental disabilities. Data suggests that services are generally improving. It will require additional time to tell whether these are results that provide solid evidence of an emerging system of reliable services. The answer to this question should become clearer over the course of the next year as the performance of providers, Service Coordinators, and others within the system is tested frequently through monitoring of different types.

In spite of the intensive systems change efforts driving improvements, we continue to meet people whose expectations of and for people with developmental disabilities are low. This is concerning because it could slow or hamper the progress needed to fundamentally change quality of daily life experiences for people receiving services. The District's Department on Disability Services (DDS), the *Evans* Court Monitor, and Quality Trust have now collected and shared data regarding areas of relative strength and weakness, and this information is now becoming well understood. Some variance in services can be linked to the complexity of individual needs for support. Other trends have been linked to individual provider capacity and skill. Providers who have embraced the need to improve the services provided by their agencies can be identified through the data. Their commitment to train employees and to provide better supervision by and of mid-level managers is evidenced in the performance data we collect. At the same time, the providers whose performance is consistently poor are also recognizable. A key question to consider is, "Are the government systems for sanctioning and removing providers adequate?" Continued progress rests, in part, on an efficient provider contracting and management system since the services to people are provided through contracts with community providers.

The highly anticipated renewal application of the Home & Community Based Medicaid waiver was approved by the Centers for Medicare and Medicaid Services (CMS) and implemented in November of 2012. After many years of discussion, a new rate methodology for reimbursing providers of intermediate care facilities for people with intellectual and other developmental Disabilities (ICF/IDD) was finally developed for implementation around the same time. That initiative has not been implemented yet, and doing so is important because of the significance of this work cannot be understated. The model it replaced had been in operation since the 1980s and was woefully inadequate in a number of different ways. In perhaps the most important development of all, three of the remaining nine areas requiring completion in the *Evans* case were certified as in substantial compliance at the October 26, 2012 status hearing. Achieving this outcome was a milestone in the now 34 year old class action litigation and represents the culmination of a great deal of work begun as far back as 2006.

Progress in the *Evans* case means changes for Quality Trust as well. As a part of the 2001 Plan for Compliance in the *Evans* case, responsibility for monitoring starts shifting to Quality Trust as court orders are satisfied, with Quality Trust completely assuming the role of independent monitor after the case has been concluded. We have been actively planning for this new responsibility and are well-positioned to take this next step. We see our work as occurring in two distinct phases. One is a short term approach to monitoring for class members in areas where court orders have been satisfied while the case is still open. The other involves developing a model that can address monitoring for all people receiving services in the District of Columbia once the case has been concluded.

We anticipate our post-lawsuit monitoring will concentrate on the capacity of DDS funded providers and Service Coordinators to support all people- class members who lived at Forrest Haven and younger people who have never been institutionalized. Court monitoring tied to standards and expectations from 1978 has addressed minimum expectations for health, safety, programming, and protection from harm. While these elements are essential, there is much more required to have a meaningful life. Expectations for basic standards of professional practice have changed significantly in the last three decades. Having friends with and without disabilities, having jobs in community businesses for real pay, freely moving about the city, and engaging in activities defined by individual interests are now seen as necessary for a full and meaningful life and will be integrated into our monitoring once the *Evans* case has ended.

Since 2008, we have concentrated our work on non-class members who live outside of the family home. This focus enabled us to ensure that standards for services delivered to non-class members did not differ significantly from class members. Having completed approximately 800 monitoring reviews within this group of people over the past five years, we decided in FY 2014 to focus on non-class members who reside with family. To the best of our knowledge, no report has been produced that focuses on this group of people and their families. We seek to highlight the demographics, needs, and aspirations of this group of non-class members and those who support them.

In addition to our direct collection of data from our monitoring reviews of non-class members, we collect and analyze other data as well. Members of our monitoring team are participants in the joint monitoring activities occurring under the direction of the *Evans* Court Monitor. Quality Trust's monitoring team also reviews and analyzes incident and investigation reports involving non-class members received throughout the year. Our legal team has access to information on the use of restrictive control procedures through our participation on the Restrictive Control Review and Human Rights Advisory Committees and the regular receipt and review of minutes of these meetings. The results of all these activities also are reflected in this report.

METHODOLOGY

Data collected solely by the QT monitoring unit focuses on non-*Evans*-class members receiving services outside of their family home. However, our tool and the manner in which we complete our work are closely aligned with that used by the *Evans* Court Monitor and the Joint Monitoring teams, who are reviewing specific services provided to *Evans* class members -- a vast number of whom also live outside of any family setting. This overlap creates a body of data that is being shared by DDS, Quality Trust, and the *Evans* Court Monitor. DDS has recently introduced a residential monitoring tool that is also similar to the tool used by Quality Trust and the Joint Monitoring Team. This is a positive development that will support continued progress in the effort to improve quality in services.

Our random sample of non-class members is selected using "Sampling: A Practical Guide for Quality Management in Home & Community-Based Waiver Program" as a guide². We have found this model to be a good fit for our needs and plan to continue its use.

² Ruth Freedman & Sarah Taub, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs (Human Services Research Institute & Medstat Group, Inc. dev., National Quality Contractor 2006).

This year, DDS provided us with the names of all non-*Evans*-class members residing in “full residential” services. We then subtracted from that list the people we reviewed last year. The resulting list consisted of 532 names, which is the group of people we are studying. As before, it is our preference to have a 95% confidence level and a confidence interval of 5%. We used Random Integer Generator to produce a True Random Number sequence, which we then matched to the corresponding names in the information provided by DDS. This resulted in 207 reviews of non-*Evans*-class members.

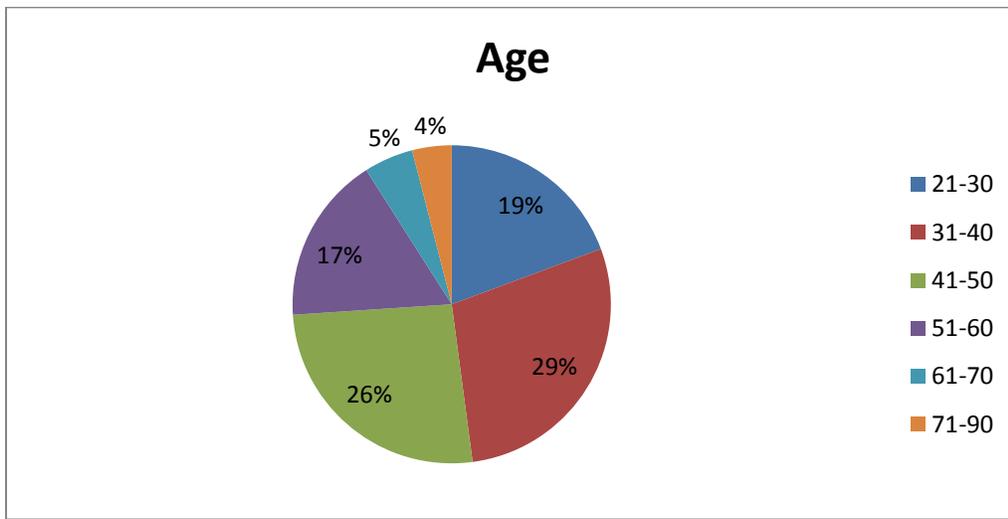
Additionally, Quality Trust’s monitoring unit receives reviews and analyzes incident management data for both class members and non-class members. The incident management sections of this report reflect the results for everyone currently receiving services through the DC Developmental Disabilities Administration (DDA).

DEMOGRAPHICS

Non-Class Members Reviewed by Quality Trust:

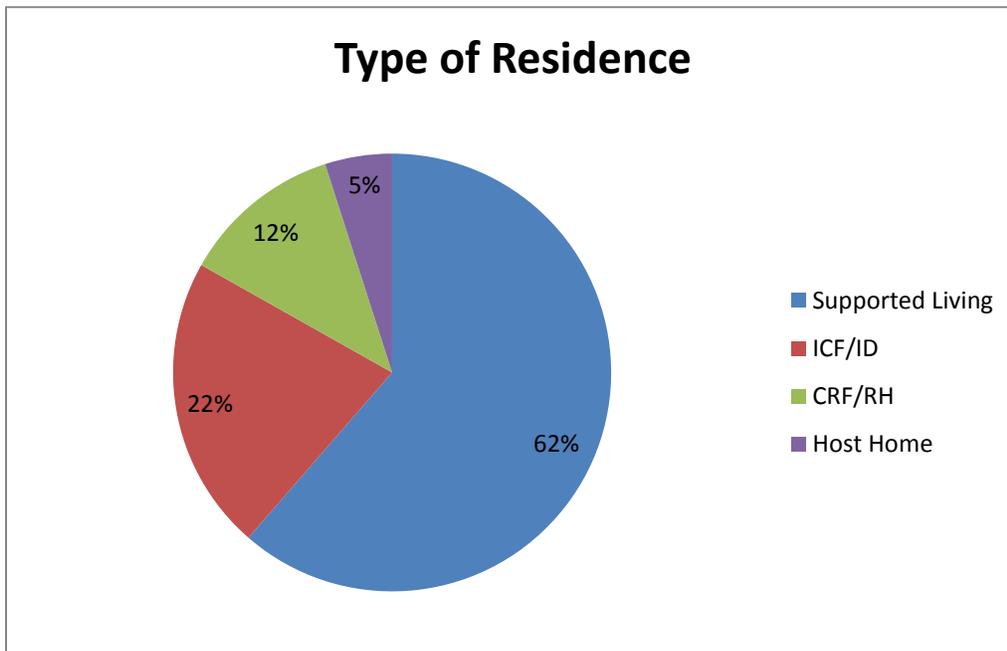
According to the Developmental Disabilities Administration (DDA), there are now approximately 1535 non-*Evans*-class members receiving services and supports.³ Approximately 800 non-class members live outside of the family home and receive residential services. The data set we studied was comprised of 530 people. We arrived at this number by reviewing the list provided by DDA and subtracting people we reviewed last year, people living out of state, and people living on their own with the assistance of little to no residential supports and services. From there, we generated a statistically significant random sample of 207 people to monitor. The information in this section regarding these 207 people are broken down relative to age, diagnosis, type of residence, and source of funding.

Age: 74% of the people our monitors met this year were between the ages of 21 and 50 years.



³MCIS Report, viewed January 16, 2013 (on file with the author).

Type of Residence



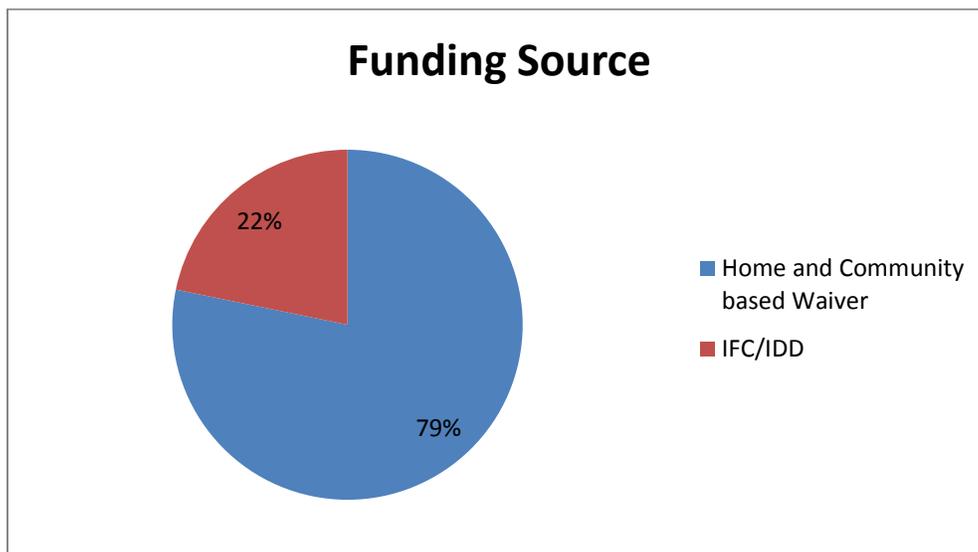
129 (62%) people lived in Supported Living, funded through the Home and Community Based Services (HCBS) Waiver

46 people (22%) lived in Intermediate Care Facilities for People with Intellectual and other Developmental Disabilities

The other 35 people (17%) lived in Residential Habilitation, and Host Homes - both services through the Waiver

Funding Source: The HCBS waiver continues to grow while ICF/IDD placements have declined. This pattern has remained consistent since we began issuing our reports in 2008.

As we noted last year, there are 2,129 people who receive services and supports through DDA. Of that total, 1585 (72%) are non-*Evans*-class members, while approximately 544 class members receive services. Approximately 1,535 people receive services through the HCBS waiver, 354 live in ICF/s/IDD, and 240 people receive through neither of those sources.



Conclusions

There were 2,129 people receiving supports funded through DDA as of January 22, 2013. The number of non-*Evans*-class members continues to grow each year, and the number of *Evans* class members is declining. As the overall number of people served grows, the system is trending to younger people who have never experienced institutional living arrangements. As in previous years, most of the people we met (74%) were between 21 and 50 years of age.

Our data also shows the continued growth of people living in supported living arrangements (vs. traditional group living). This option is among the least restrictive types of formal residential service available in the District. Interesting, the second most utilized living arrangement for the people we met this year was the intermediate care facilities for people with intellectual and other developmental Disabilities (ICF/IDD), which is typically recognized as among the most restrictive alternatives. This trend has been present in every report we have completed since 2008. Two other models offered through the waiver rounded out the options utilized by the people we met. Residential Habilitation, a group home living arrangement through the HCBS waiver, was the third most utilized option. The Host Home option, in which people with disabilities live in private homes, has grown slowly since it was introduced in 2008.

PERSONAL INTERVIEWS

The personal interview is perhaps the single most important component of our data collection. Through this process, we consistently observe that many people we meet live anonymously, even though they are surrounded by other people. In practical terms, this means that too often the people who are paid to provide direct, day-to-day support do not know basic information about the people with disabilities they are supposed to assist, including basic details such as age, personal history, preferences, and goals for the future. Since adequacy and quality in service is linked to meeting unique, individual needs for support, we start with asking each person to tell us who they are, what they want, and as much about their lives as possible. While we make every attempt to collect information directly from each person, there are times this is not possible given the person's disability or communication style. At those times, we rely on direct observation and input from those who know the person best to assist us to understand the preferences, priorities, and means of communication for the person being reviewed. When we utilize information provided by others, we always follow-up with additional probative questions to ensure the greatest accuracy of information gathered.

The following information relating to choice and autonomy is derived from our personal interviews of the people we met during our monitoring this year. These results reflect an *N* of 204 people, as 3 people declined to proceed with the interview.

- 170 (83%) people reported they had active family involved in their life;
- 159 (78%) people reported they had active friends (usually housemates);
- 93 (46%) people reported that they had friends without disabilities;
- 194 (95%) reported that were able to invite a family member or friend to their ISP meeting;
- 196 (96%) people reported that they liked their home;
- 178 (87%) reported that they have met their neighbor;

- 204 (100%) reported that they have privacy in their home when they need or want it;
- 158 (77%) report that they participate in their grocery shopping;
- 197 (97%) report that they participate in purchasing their clothes;
- 152 (75%) report that they participate in their personal banking; and
- 161 (79%) report that they have their own bedroom.

Conclusions

As with several other data elements in this report, indices of personal choice and satisfaction rose again this year. Positive scores are noted for most of the questions we asked. However, one significant hurdle yet to overcome is the low incidence of people enjoying meaningful relationships with people without disabilities. While people report that they have friends without disabilities, people often identify staff as friends. While it is good that people with disabilities feel positive toward their staff, these paid relationships do not replace the need for genuine, freely given friendships. Another related challenge remains in the area of day programming, where the number of people working is limited and most people spend their days in segregated situations where daily contact with people without disabilities is limited.

INDIVIDUAL SUPPORT PLANS (ISPs)

Current ISPs

Of the 207 people reviewed, 190 (92%) had a current, approved Individual Support Plan (ISP). This is a 4% increase from last year and an 18% increase from the findings in our 2009 report. This is a clear improvement. However, we continue to have concerns about the quality of the ISPs. These results reflect an *N* of 190 people, as 17 people did not have current, approved ISPs at the time of the review.

Our findings included the following:

- 171 (90%) ISPs contained measureable criteria by which the team could determine when the goal/outcome(s) had been achieved;
- 161 (85%) contained goals reflecting the person's preferences and needs;
- 182 (96%) contained supporting documentation which evaluates the provider's effectiveness in supporting the person to achieve their goals; and
- The area of unscheduled pre planning meetings decreased by 4% since the 2011 report. (2012 40%) vs. (2011 44%)

Conclusions

From our participation in ISP meetings, we have observed a significant range in style, demonstrated knowledge, and facilitation skill by DDA Service Coordinators and designated provider staff. While our data supports the conclusion that the process is improving overall, we still see instances when this process does not result in a plan that reflects individually identified priorities or protects people's most basic human and civil rights.

We note that DDS has recently initiated an effort to promote Person Centered Thinking by bringing in a national expert to conduct training in this area. There is similar work being done by DDS to promote integrated employment opportunities as well. It is important that this kind of thinking inform the development of ISPs if services and supports are to become more tailored

and responsive to individual needs. Training on person-centeredness alone has not resulted in significant changes for people in the past. DDS Service Coordinators play a significant role in ensuring that planning meetings are focused on the person and plans reflect what is most important to the person and will need to take a leadership role in order to drive the change in practice.

REVIEW OF HEALTHCARE

Health Management Care Plans, Medical Follow Up and Health Passports

Providing nursing and other medical services and supports has been a challenge in the District of Columbia for many years. The *Evans* litigation has focused much attention on this area. Countless initiatives, workgroups, consultants, and experts have worked to identify, develop and implement policies and practices intended to improve health outcomes for people receiving services and supports. While improvements have been achieved, the quality of individual support often depends on the ability of the provider to hire and retain qualified nurses and clinicians. A well-developed procedure for sharing information between clinical and non-clinical staff also is critically important. These facts have been highlighted in Death Investigations and investigations of the root causes for Emergency Inpatient Hospitalizations for some time now.

Nurses and clinical staff must ensure that Direct Support Professionals (DSPs) have the training and skill to identify signs and symptoms associated with specific medical issues experienced by the people they support. They must also be assisted to understand the person's health concerns well enough to actively manage and coordinate those needs with licensed professionals. We look to see evidence of this in practice when we complete our monitoring reviews. Our Monitors review medical records to determine whether each person has a Health Management Care Plan. Through interviews with DSPs and clinical staff, we assess whether this plan is understood and being implemented. Our findings this year indicate that there is progress with developing and implementing Health Management Care Plans for the people we reviewed.

- 190 people reviewed (92%) had a current Health Management Care Plan;
- 154 people (79%) had all of their follow up appointments or labs completed as scheduled;
- 194 people (94%) had a current Health Passport.

Review of Death Investigations for Thirteen Non-*Evans*-class Members

Last year we completed an analysis of 91 Serious Reportable Incidents involving Emergency Inpatient Hospitalizations of non-*Evans*-class members. We did so because we noted that unplanned trips to the emergency room has been the largest category of incident affecting both class and non-class members for many years. We were trying to understand if incidents in this category could have reasonably been avoided. It was our opinion that approximately 30% of the admissions we reviewed were avoidable. Some of the factors that lead to our conclusion were: the presence of signs and symptoms of illness for 48 hours without adequate response from provider nursing staff, limited or poor communication between the nursing staff and the primary care physician, and limited or poor communication between provider nurses and the DSPs they oversee regarding health and medical services.

We were encouraged that in September of 2012, DDA Incident Management and Enforcement Unit (IMEU) investigations of Emergency Inpatient Hospitalizations began to include an analysis

of whether or not negligence by the provider led to the hospitalization. According to the Chief of IMEU, an analysis of the outcomes of that work is not available and will be forwarded to Quality Trust at a later date.

This year we completed a qualitative review and analysis of the Mortality Investigations of non-*Evans*-class members we received throughout the fiscal year. A total of 13 of 21 investigations reports received were reviewed for non-class members. These reports are completed by an independent contractor, the Columbus Organization. Our review was completed by Quality Trust's Health Monitoring Coordinator who is also a registered nurse. This process involved a review of the Columbus Mortality Investigations with a focus on statements contained in the sections titled "Areas of Concern", "Recommendations for DDS", and "Recommendations for the Provider". The findings below reflect a summary of the data we reviewed and "themes" identified during this review.

Findings:

- (6) involved individuals with Hospice in place or classified as "Do Not Resuscitate" (DNR) which is indicative of a terminal illness;
- (3) of the deaths involved people in their 20's; (3) in their 30's;
- (4) were in their 40's;
- (1) in their 50's; and
- (2) in their 60's –
- These ages are significantly younger life expectancy than the average of mid-50's to mid-70's depending on the severity of the intellectual and developmental disability.⁴

Regarding the living arrangements of the non-class members, we found that:

- (2) lived in natural homes with provider agency in-home supports;
- (2) died in LTC or LTAC facilities; and
- (9) lived in out of the home placements through provider agencies.

Trending of the Investigations revealed:

- (11) of the concerns/recommendations involved a reference to Service Coordination or provider oversight. Examples are:
 - (3) involved incorrect information (names) in ISPs.
 - (6) of the Mortality Investigations referenced improperly trained staff.
 - (4) of the investigations referenced staff training related to 911/emergency procedures. Specifically:
 - Transporting people to the ER in the van rather than calling 911
 - Delay and confusion in starting CPR
 - Evacuation in emergency
 - (1) noted a lack of follow-up with specialist recommendations (no ramp was installed at a natural home where a person using a wheelchair lived)
 - (6) contained recommendations that "DDS should ensure that the Service Coordinator is completing and documenting the required monthly face-to-face visits and the monitoring tools." *
 - (2) noted lack of documentation regarding formal "End-of-Life" planning
- (10) of the concerns/recommendations referenced problems with Registered Nursing oversight.

⁴ Tamar Heller, *People with Intellectual and Developmental Disabilities Growing Old: An Overview*, 23 IMPACT 2, 2-3 (Winter 2010).

- (8) of the individuals did not have a complete/current list of medical/health problems.
- (9) noted incomplete, non-current, and/or non-person centered Health Management Care Plan interventions.
- (8) referenced Health Passports that were incomplete or not current.
- (7) contained issues surrounding transcription errors with physician orders/Medication Administration records errors in routine or PRN orders;
- Other areas of concern included failures by providers around staff training:
 - A Direct Support Professional that supported one person failed to note that the person had not had a bowel movement for three days. As a result there was no intervention. That person eventually succumbed after an emergency bowel resection.
 - A Direct Support Professional was not trained on medication side effects and reporting changes in a person's condition to supervisors in a timely fashion
 - Incorrect and/or missing data on immunizations was noted
 - Seizure records were incomplete and seizure descriptions were not documented

While this was a simple sampling of the investigation reports received, we noted concerns about staff training, inconsistent oversight, and failures by Registered Nurses relative to the ensuring the health and safety of non-*Evans*-class members. The DDS/DDA Mortality Review Committee currently reviews each of the Columbus Mortality Investigations and makes recommendations to DDA based on the findings. The work of this committee is vitally important as the group reviews investigation reports for every person receiving services who dies and can make important recommendations regarding needed safeguards and service changes. We would like to see an analysis of the recommendations made by this committee and tracking of progress based on this analysis. We also support DDS using its newly constituted sanctions procedure to deal with providers found to perform poorly in this critical area. DDA should also continue to exercise a similarly rigorous response with Service Coordinators and their Supervisors who fail to catch problems before they threaten the health and well-being of people receiving services-especially those non class members who reside at home with family.

Our monitoring in the area of health demonstrates that there have been improvements, yet there is still room for improvement. Because health and safety is such a critical area for people receiving services, continued vigilance is required. Monitoring and follow-up of Mortality Review Investigations, Provider Certification Reviews, Serious Reportable Incidents, Service Coordination Monitoring Tools, and Health & Wellness reports are all important tools for performance tracking and analysis. The DDA's overall work to strengthen its systems for data tracking and analysis has contributed to improving the type and amount of data available for review. Continued enhancement of analytical capabilities of recurrent themes and less tolerance for failure in these areas are essential if issues are to be significantly reduced or eliminated.

We did not meet enough people this year whose medical profile rose to the level of requiring full participation from our Health Monitoring Coordinator. For that reason, we do not have statistically significant data from her situational involvement with specific people. Our practice is to have our Health Monitoring Coordinator participate in the individual monitoring review whenever our monitors encounter either extensive health care needs or particularly troubling provision of nursing services.

REVIEW OF BEHAVIOR SUPPORT PLANS

Quality Trust serves on the DDA's Human Rights Advisory Committee (HRAC) and its subcommittee, the Restrictive Control Review Committee (RCRC). Under current DDA policy, all Behavior Support Plans (BSPs) utilizing restrictive controls must be reviewed and approved by HRAC and RCRC prior to implementation.⁵ Restrictive controls include any device and/or procedure that: (1) restricts, limits, or directs a person's freedom of movement (e.g., mechanical restraint, manual restraint, one-to-one staffing, or time out procedures); (2) restricts access to personal property or removes something the person owns or has earned; (3) is prescribed medication to stabilize, alter and/or change behavior or mood; or (4) may compromise the human or civil rights of a person.⁶

Over the past year, Quality Trust participated in the review of a total of 615 BSPs for both *Evans* class and non-class members.⁷ For the purposes of this report, we focused on the subset of plans for non-class members – of which there were a total of 276 BSPs for 227 people. A look back at the plans and the review process demonstrate some significant weaknesses with providers of mental health and behavioral support services, provider Human Rights Committees (HRC), and with DDA procedures and practices. We noted some encouraging areas of improvement within DDA are well. The following describes our major findings and conclusions.

DDA's Focus on *Evans* Class Members Versus Non-Class Members

Overall, we found that DDA focused much of its committee work on reviewing BSPs for *Evans* class members, rather than non-class members. Of the 615 BSPs reviewed by RCRC and/or HRAC during the year, less than half (45%; 276/615) were for non-class members. The remaining 55% (339/615) were for class members. Our demographic data reflects that class members comprise only 28% of the people who receive services from DDA.

We did see a shift at DDA that increased the number of non-class member BSPs reviewed in the second half of fiscal year 2012 – which is encouraging. During the first six months, only 25% (69/274) of BSPs reviewed by RCRC were for non-class members; during the last six months, this percentage increased to 61% (207/341). We believe that this shift was driven in part by DDA's focus on reviewing BSPs of people in ICF/IDDs, in order to facilitate the then-upcoming implementation of new emergency rules on Medicaid reimbursement rates for ICF/IDD providers.⁸ Therefore, we continue to be concerned that some non-class members are not having their BSPs reviewed in a timely manner.

⁵ See DDA Behavior Support Policy at § 4.G (August 2, 2011), available at <http://dds.dc.gov/DC/DDS/Developmental+Disabilities+Administration/Policies/BSP+Policy+8+2+11> (last visited January 25, 2013) (hereafter, "BSP Policy").

⁶ See DDS Definition Appendix, available at <https://sites.google.com/a/dc.gov/dds-definitions-appendix> (last visited January 25, 2013) (defining "Restrictive Control").

⁷ Some plans that the committees reject or approve with modification come back to the committees to be reviewed after modifications are made. Also, although the data is being described as being for the 2012 fiscal year, Quality Trust did not start collecting it until its Legal Department began attending RCRC meetings on October 18, 2011. Therefore, any data from October 1 through 17, 2011, is not included in this data set, although there may have been an RCRC meeting in early October.

⁸ See Notice of Emergency and Proposed Rulemaking, Medicaid Reimbursement for Intermediate Care Facilities for Individuals with Intellectual Disabilities, D.C. Register Notice ID 2563797, Vol. 59/39 (September 28, 2012), available at <http://www.dcregs.dc.gov/Gateway/NoticeHome.aspx?noticeid=3563797> (last visited January 25, 2013).

DDA has not been able to provide Quality Trust with concrete figures on how many non-class members have BSPs or how many are waiting for review by RCRC or HRAC. We have learned that this information is not currently being tracked by DDA, although we know that it is for *Evans* class members. We are concerned that there is no current method within DDA to prompt the review of non-class members' BSPs. Without consistent tracking, the scope of committee work and any backlog is unclear, which is particularly troubling given that the majority of BSPs reviewed by RCRC or HRAC are not approved as written.

DDA has informed us that improvements in data collection which will track the status of current BSPs are in development and was scheduled to be implemented in January 2013. It is important that the system implemented cover all people receiving supports and services from DDA to avoid a bifurcated system that disadvantages the ever-growing population of people who are not members of the *Evans* class.

Long Delays from When a BSP is Written until it is Reviewed By RCRC or HRAC

We noted a wide range of waiting times for non-class member BSPs to be reviewed by RCRC or HRAC, with the greatest being 548 days and the shortest time being 12 days. Part of the reason for some of the shorter timeframes was that the RCRC or HRAC rejected a previous version of the BSP, with the revised plan later coming back to the committee and being tracked from the date of revision, rather than the original plan date. The average wait time was 165 days – *i.e.*, around 5 ½ months – from the time the plan is written until it is reviewed.

These delays are concerning, because, while the BSPs are awaiting review by DDA, providers have already approved them through their HRCs, trained their staff on the plans, and are using them to support people. Moreover, BSPs generally are current for only 12 months.

We are encouraged by the enhanced effort of DDA to review BSPs over the last year, which has included the addition of a second RCRC and more frequent and longer RCRC meetings. However, we remain concerned about the wait time for RCRC/HRAC review, particularly for non-class members, whose BSPs are not currently subject to the same DDA tracking as the *Evans* class members.

Most Plans are Not Approved as Written by DDA through RCRC and HRAC

Of the BSPs reviewed for non-class members, only 11% (30/276) were approved as written. Another 42% (115/276) of those BSPs were approved with qualifications, which included the committee limiting the length of time of the qualified approval. Almost half – 46% (129/276) – of the BSP were rejected and sent back with suggestions for a rewrite. Two plans were neither approved nor rejected, but instead discontinued by the committee as not necessary.

Our review found a number of serious concerns with proposed BSPs for non-class members:

- 48% (132/276) of the BSPs had components that were too negative or restrictive.
- There were issues with data and/or data tracking in 46% (128/276) of the BSPs. BSPs generally must include a year's worth of data on a person's target behaviors,⁹ so that

⁹ See DDA Behavior Support Plan Procedure at § 3.B.14 & 16 (August 1, 2011), available at <http://dds.dc.gov/DC/DDS/Developmental+Disabilities+Administration/Policies/BSP+Procedure+8+1+11> (last visited on January 25, 2013) (hereafter "BSP Procedure"); DDA Behavior Support Plan Template at

there can be an assessment of the effectiveness of interventions, the continued justification of any restrictive controls, and the progress a person and his or her providers are making in achieving behavioral goals.

- There was an inadequate functional analysis or concerns about suggested replacement behaviors in 41% (112/276) of the BSPs. BSPs must include a summary of the proposed function of each target behavior¹⁰ and identify and promote alternative skills and actions that the person can use instead that will serve that same function.¹¹
- There was a concern about the prescribed medication(s) in 33% (92/276) of the BSPs.
- 26% (71/276) of the BSPs had no fade plan or an inadequate fade plan. BSPs must describe a clear plan for reducing, facing, or eliminating the use of restrictive control procedures, including psychotropic medications.¹²
- There was a concern with the Axis I diagnosis in 22% (61/276) of the BSPs. Under DDA Policy, psychotropic medications must be linked to a corresponding Axis I diagnosis in order to be justified.¹³
- 5% (15/276) of the BSPs had no crisis plan or an inadequate crisis plan. BSPs must describe the specific procedures for supporting people during crisis events.¹⁴

We find it positive that DDA does not approve insufficient BSPs as written, and we have found the RCRC and HRAC reviews to be thorough and meaningful. However, that the above plans were approved by the provider HRC, before being sent for review by the DDA committee leads to significant concerns about provider capacity and practice. It points to the need for ongoing training and guidance for provider HRCs to ensure that their members are following DDA policies, procedures and standards regarding acceptable BSP's.

We know that DDA has increased training opportunities for the psychologists who write BSPs. We are hopeful that this effort will result in higher quality and more person-centered BSPs, which focus on positive behavioral supports, rather than, eliminating a person's so-called "problem behaviors" as defined by the provider. We also support DDA's enforcement efforts at the provider level to address the inadequacy of BSPs – e.g., by making BSPs that have been rejected or approved with qualifications compliance issues that are followed up on by DDA's Provider Resource Management Unit. DDA must be prepared to take action against providers, where needed, to create financial and other disincentives that will trickle down to the psychologists they pay, so that the quality of BSPs improve and the number of rejections and committee-requested modifications to BSPs can decrease.

§ 6, available at http://dds.dc.gov/DC/DDS/Developmental+Disabilities+Administration/Policies/BSP+Policy+Attachment_BSP+template8+2+11 (last visited on January 25, 2013).

¹⁰ See BSP Procedure, supra note 7, at § 3.B.8; BSP Policy, supra note 3, at § 6.F.

¹¹ See BSP Procedure, supra note 3, at § 3.B.10.

¹² See id at § 3.B.14.

¹³ See DDA Human Rights Policy at § 6.9.s (August 1, 2011), available at <http://dds.dc.gov/DC/DDS/Developmental+Disabilities+Administration/Policies/Human+Rights+Policy+8+2011> (last visited on January 25, 2013).

¹⁴ See BSP Procedure, supra note 3, at § 3.B.12,

INCIDENTS AND INVESTIGATIONS

This section includes an analysis of data collected covering ALL people receiving services in the District of Columbia – *i.e.*, both *Evans* class members and those who did not live at Forest Haven. Quality Trust receives notification of all Serious Reportable Incidents (SRIs) filed for anyone receiving services through the DDS/DDA. We complete a detailed review and triage process for incidents involving non-class members, as well as a Qualitative Review of investigations for non-class members. By agreement with the Court Monitor, we also provide analysis as directed for incidents and investigations involving *Evans* class members.

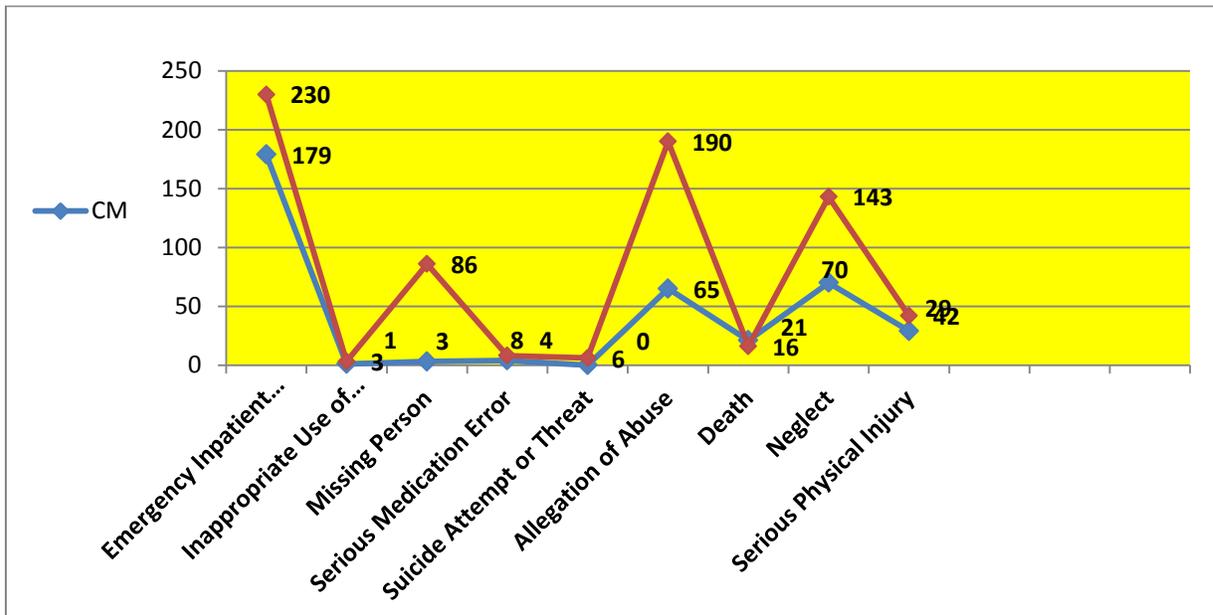
It has now been two years since DDA revised its IMEU policy. Two of the most important changes included longer timeframes for providers to complete their internal investigations, and a process for IMEU staff to “grade” provider investigations. Providers who demonstrated consistently high quality investigations would receive less oversight by IMEU, while those needing more support would receive the training necessary to receive less supervision. A sustained score of 4.0 (Exceeds Expectations) or better is cited in the policy as the score providers needed to attain to gain greater independence.

According to the Chief of IMEU, as of the end of FY 2012, there were no providers who have attained a sustained score of 4.0. Twenty-two providers have maintained a score of 3.0 (Met Expectations), but thirty-five providers have scored 2.9 or below (Below Expectations).

As part of DDS’ Systems Improvement Plan for Quality Assurance, the IMEU policy is once again under revision. As the 2010 policy has been implemented, we have noted that the number of overdue investigations for both *Evans* class and non-class members has been significantly reduced. Further, when investigations are overdue, the number of days is generally less than fifteen. We have nonetheless noted a practice (not described in either the current policy or the draft of the new policy) of allowing up to 60 days beyond the completion of the investigation to verify that recommendations made are implemented. We believe this practice weakens the policy relative to protecting people from potential harm. We have recommended and support a timeframe for completion of no more than 5 days from the completion of the investigation.

Serious Reportable Incidents: During the period from October 1, 2011, through September 30, 2012, 724 Serious Reportable Incidents (SRIs) were reported for non-class members, which accounts for (66%) of the total of 1,096 reported for people receiving services in DC. We completed 714 triage reports (notifications of death are not triaged), including tracking and trending analysis for these SRIs. There were 372 (34%) incidents reported for Class Members. We completed 209 (56%) reviews involving investigations of those incidents which focused on provider compliance with implementing recommendations contained in the investigations.

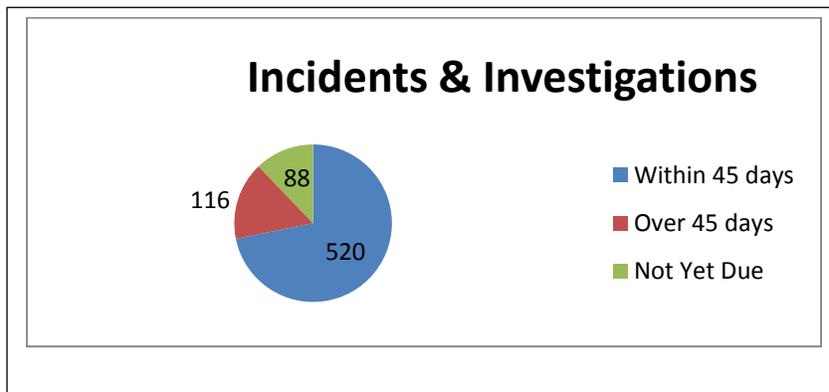
Incident Breakdowns between Class and Non-Class Members



Serious Reportable Incidents & Investigations

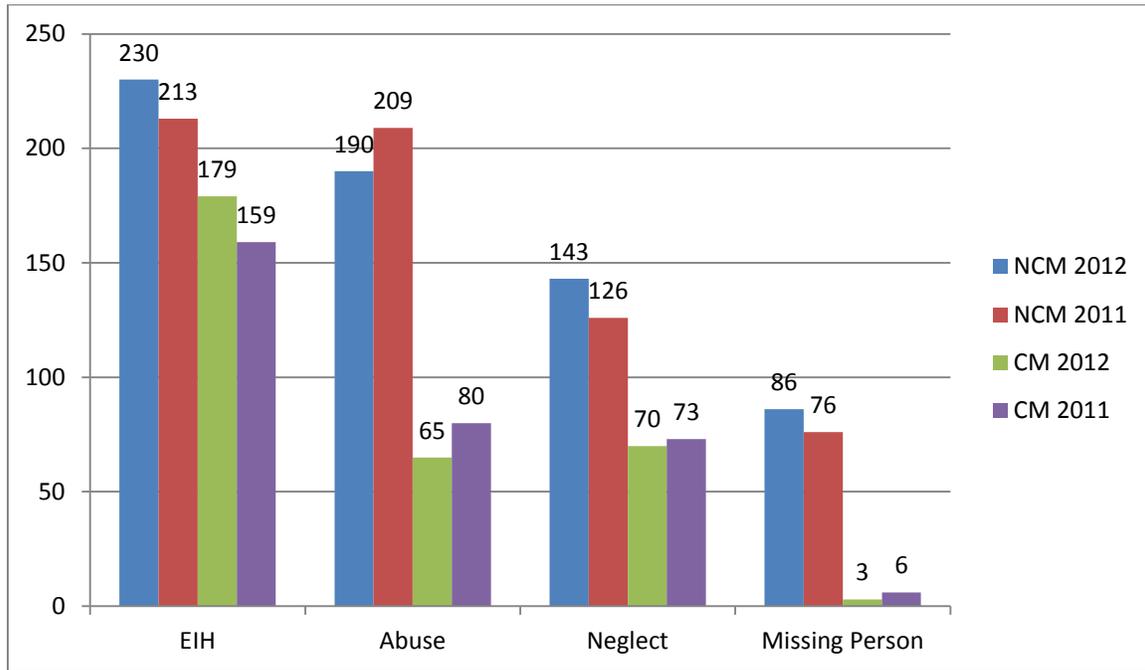
Quality Trust tracks investigations for all SRIs, the timeframe in which they are investigated or closed, and how they were closed. The numbers below reflect data regarding only non-class members (NCM) from October 1, 2011, through September 30, 2012 (724 SRIs). There were 636 investigations due as of September 30, 2012.

The number of SRIs rose modestly from 1053 in FY 2011 to 1096 in FY 2012.

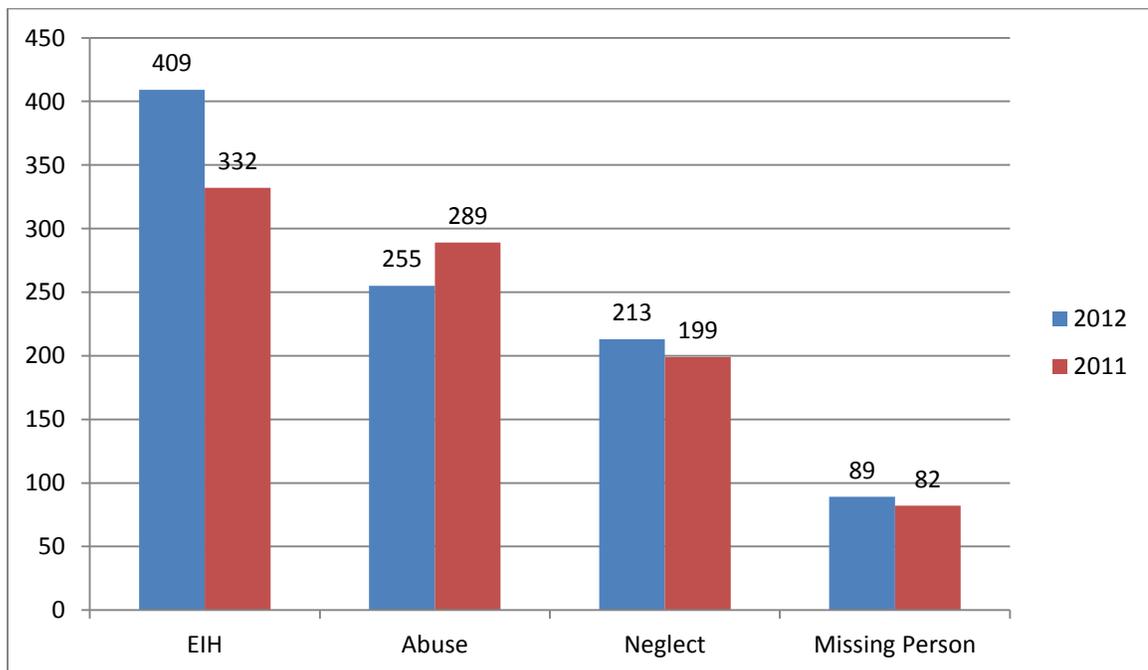


- 81% (520) of NCM investigations were completed within the 45 day timeframe
- 18% (116) of NCM investigations were not completed within the 45 day timeframe
- 14% (88) investigations were not yet due as of the last day of the fiscal year

**Incident Comparison Non-Class Members and Class Members
FY 2011 and FY 2012**



Total Incident Comparison FY 2011 and FY 2012



- Once again, Emergency Inpatient Hospitalizations (EHI) remain the single highest incident type at 409;
- Allegations of Abuse decreased from 289 last year, to 255 this year;
- Neglect increased from 199 incidents last year to 213 this year;
- The largest area of variation in results between class and non-class members was in the Missing Person category; 86 NCM, and 3 CM;
- As we noted last year, a small percentage of non-class members accounted for most of these incidents, and were due to people leaving their home without informing staff, or after they had been instructed not to leave.

Triage of Serious Reportable Incidents

As part of our review of SRIs involving non-*Evans*-class members we complete a triage form designed to provide us with a sense of what is happening for a person at a given time, assess the need for potential intervention, and help us track and trend incidents. The following is a summary of our findings based on the 714 triage documents (99%) completed:

- We found evidence of Service Coordinator follow up regarding 49% of the SRIs;
- We found evidence that Service Coordinators completed the required 4 monitoring tools (for people receiving waiver services) in 64% of the cases we reviewed;
- 41% of the people reviewed had at least one similar incident over the past year;

Qualitative Review of Investigations of Serious Reportable Incidents

Our qualitative look at investigations of SRIs involving non-*Evans*-class members consisted of a review of 689 (95%) of 724 investigations. We utilized the “Checklist for Reviewing Investigation Quality,” which is based on the same tool used by IMEU investigators per DDA policy.

Overall, the quality of the investigation reports continued to improve. Significant improvement is evident in comparison to the reports reviewed in previous years, and on-going improvement was noted throughout the year. Nonetheless, the data indicates that there is still more improvement needed to reach consistency, with established standards of practice in incident investigation. Our review of the investigations found that:

- A site visit was completed in 87% (314) of the investigations;
- The site visit was completed within 24 hours in 15% (55) of the investigations;
- 85% of the investigations included documentation of an interview with the person;
- 73% contained evidence of a review of the alleged perpetrator’s background information;
- 80% included evidence of a review of previous incidents involving the person; and
- 96% of the investigations contained an analysis of the information gathered to support the conclusion.

Conclusions

There were a total of 43 more SRIs reported this year over last. Annual increases have been noted since 2008. This is to be expected, given the increasing number of people supported by the DDA and the continued focus on increasing provider capacity to report and investigate incidents. Unplanned trips to the emergency room continue to be the largest category of incident reported.

DDA Service Coordinators are expected to follow-up with the person and the provider agency after incidents are reported as part of their professional responsibility, to assist the person and ensure delivery of adequate and responsive services. As measured in our triage process, we found follow up after notification of SRIs 49% of the time. Our criterion in this regard is a progress note describing the fact that within 24 hours of the Service Coordinators being made aware that some type of action (e.g., a phone call, or face-to-face visit) was completed. We do not credit a statement of notification only as follow up. We also check to see if the correct number of Monitoring Tools required by DDA policy has been completed. We note the total number of tools and the required number of site specific monitoring tools as mandated in the policy.

We continue to express concern that the current IMEU policy mandates that a site visit be completed by investigators within 24 hours of the date the SRI is received by the IMEU rather than the date the incident occurred. It is our opinion that someone other than the provider should secure the scene within 24 hours of the incident in cases of abuse, neglect, serious physical injury, and death – especially when the provider has not demonstrated proficiency in the completion of investigation reports. Independent review of the most serious incidents should be an earned privilege afforded to the best performing providers.

We also believe the current practice in place to ensure that recommendations to protect the health and safety have been implemented is inadequate. Based on our data, it appears that confirmation that recommendations have been implemented takes approximately 30-60 days beyond the 45 day period allotted for completing the investigation.

FINAL COMMENTS

As we noted at the beginning of this report, people receiving services need and want the people assisting them to believe in their capacity to learn and develop over time. They need to trust that those around them understand who they are and will tailor the support provided to address their most pressing needs. Although the people in the DDA system share the label of intellectual and developmental disabilities, they represent a diverse constituency with many varied needs. High quality supports are responsive to these individual differences and offer different opportunities and assistance to different people based on their unique needs.

Consistent with the original mandate outlined for Quality Trust in the 2001 Settlement Agreement, our expectations for services and service providers are tied to the standards set by federal funding programs (ICF/IDD, Medicaid Waiver) and nationally recognized organizations. We envision services that are responsive to the individual needs of each person in addition to meeting minimum requirements for ensuring health, safety and compliance with local policies and rules. Unfortunately, many providers struggle to meet these standards. True improvement will only occur when those receiving services are viewed as valued people, with important needs and desires like any other person.

This report indicates there have been encouraging changes and ongoing improvements are being made. At the same time, the failure of some to master simple yet important aspects of supporting people with developmental disabilities is hampering progress. While some of these observations are not formally counted in this report, they reflect the direct interactions we have while advocating for and supporting people with disabilities throughout the system. Some of the most concerning issues are:

- Individual Service Plans (ISPs) that do not capture who people are and what they need.
- Day programs that do not engage or challenge people provided in segregated settings.
- Behavior support plans that do not promote learning and instead further stigmatize or isolate people with disabilities.

We believe change in these areas is vital to sustain the current momentum for improvement. Going forward, a highly skilled and qualified provider community will be needed to partner with the government. Meeting minimum standards for compliance with basic health and safety concerns will never be enough to sustain good outcomes for people. Significant improvements for people will only be realized when the service system is populated by professionals and providers who use best practices as a performance benchmark and aspire to continually improve services over time.