Annual Monitoring Report
and
Data Summary

October 1, 2010 – September 30, 2011

Quality Trust was created in 2001 as part of a settlement agreement in the long standing class action lawsuit, *Evans vs. the District of Columbia.* This lawsuit led to the closing of the District's institution for people with intellectual disabilities (Forest Haven) in 1991, yet remains open today given continuing concerns about the quality of community supports for class members. Quality Trust serves as the District's independent, advocacy organization leading efforts to improve government and community systems and supports for DC residents with developmental disabilities and their families. While the litigation is active, Quality Trust's monitoring is focused on assessing supports for people with developmental disabilities who are not members of the class. Quality Trust also works in concert around monitoring activities with the federal court appointed monitor in the *Evans* case. Once the lawsuit is concluded, Quality Trust will remain as an independent advocate and monitor of services for people with developmental disabilities. Our ongoing monitoring will focus on assessment of services and general conditions to promote continued improvement and safeguard against future abuse and neglect. Quality Trust also provides individual and family advocacy, legal education and advocacy and other supports for DC residents and their families.

EXECUTIVE SUMMARY

The District of Columbia government continued its reform initiatives this year in the long struggle to improve services and supports to people with developmental disabilities. Elevating the performance of the Department on Disability Services and the contracted providers who support people receiving services has been a primary focus of reforms over the past several years. Quality Trust's data indicates progress in several areas. Still, there remain significant hurdles to overcome before we can be certain that lasting advancements have been achieved. Functional, well-coordinated, partnerships between the Department on Disability Services, the Department of Healthcare Finance, and the Health Regulatory and Licensing Administration are also necessary for long term sustainable progress. In the end, we expect that the performance of providers will be the single most important variable in improving the day to day lives of people with developmental disabilities.

This report focuses on the services and supports provided to non *Evans* class members who reside outside the family home. Our tool and the manner in which we complete our work though 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.

Some of the improvements and challenges we noted are:

- After hovering in the upper 70's for the past three years, we found that 88% of the people we reviewed had a current ISP in their home, which represents a 10% increase;
- People receiving residential support funded through the Home and Community Based Services Waiver remained consistent at 74%;
- Significant improvement in satisfaction was noted in our personal interviews.

Findings regarding the provision of healthcare are mixed.

- Positively we found:
    - People with a co-existing intellectual disability and mental health diagnosis, which had been consistently in the 70% range, dipped to 62% this year;
    - 87% had a Health Management Care Plan, and
    - Everyone reviewed had documentation that the plan was monitored;
    - 92% had a current Health Passport.

- Our analysis of 92 incidents involving emergency inpatient hospitalization revealed failure by providers to prevent emergency room admissions due to:
    - An inability to effectively track and trend, or better analyze internal incident data;
    - Failure to acknowledge signs and symptoms of a developing health emergency;
    - Failure to proactively coordinate primary healthcare between a primary care physician or psychiatrist and nursing staff from the agency.

2012 will be an important test year for the work done to end the *Evans* case and build an enduring, high quality system of services and supports. The Settlement Agreement approved by the Court in August 2010 envisioned closure of all outstanding orders in the case by August 2012. The Home and Community Based Services Medicaid waiver is due to be renewed in November 2012.

Last year we concluded that, "Retention of qualified providers and dismissal of those unable to demonstrate consistently acceptable practice must be the shared outcome of government…." We hope this year is a watershed for recruitment of new and innovative providers, while continuing the systemic reforms begun over the past several years. Terminating the contracts of underperforming providers must also accelerate to bring the system to a place where the floor for performance is raised enough to ensure reasonable and reliable services across the spectrum of supports provided. We believe this is still the single most important challenge facing people with receiving services.

INTRODUCTION

Background on the Reporting Period

During FY 2011, the period covered in this report, the Department on Disability Services (DDS) engaged in internal capacity building activities such as developing new policies, enhancing the Provider Readiness Certification review process, improving the quality of Serious Reportable Investigations, and other activities designed to improve services and bring an end to the *Evans* litigation. The Independent Compliance Administrator (ICA) appointed in the *Evans* case worked with providers in a number of different areas, including preparation for the joint monitoring of their agencies, which would help determine whether the outstanding Court orders in *Evans* have been successfully remediated.

Although much of the work carried out over the past fiscal year was centered on *Evans* class members, it is the stated goal of the leadership of DDS to improve services for all people receiving services and supports in the District of Columbia. Nonetheless, changes were made to the Service Coordination policy, for example, that reduce the number of visits and monitoring tools required for non *Evans* class members. It remains to be seen what impact these changes will have on safeguarding and advocating for the best possible outcomes of non class members.

Changes in the QT Monitoring Unit

With the effort to close the *Evans* litigation in full gear, we have increased the number of staff dedicated to the Joint Monitoring process from .5 FTE to 3 FTE, with additional participation from the Monitoring Director. We also added a full time nurse to our staff in November of 2010. We see this addition as critical to our future success as we assume sole external monitoring responsibilities at the end of the *Evans* case.

Beginning in the fall of 2010, we participated in drafting the Interpretative Guidelines of the Joint Monitoring Tool. Throughout the winter of 2011, we participated in inter-rater reliability testing of the tool. Beginning in April of 2011 and continuing until August, we participated in piloting projects. Beginning in October of 2011, we began participation in the first of the Compliance Authentication exercises. We anticipate that this heightened level of activity will continue through the end of FY2012.

Despite the emphasis on participation in the Joint Monitoring process this year, we remain committed to completing significant monitoring of services to those non *Evans* class members who reside outside the family home. Our work over the coming year will focus exclusively on revisiting non class members we have met over the past two years. We hope to demonstrate whether or not progress has been made in areas such as: current ISP's, increased opportunities for real community participation, and provision of adequate healthcare services and supports.

Some highlights of our work this year include:

- 274 People Monitored/Reviewed (both *Evans* class members and non class members)
- 197 Random Reviews of non class members
- 35 Nursing Random Reviews of non class members
- 42 Evans class member reviews (28 non nursing & 14 nursing) through *Evans* Joint Monitoring
- 1052 Total Serious Reportable Incidents (SRI) Reviewed:
  - 442 SRI reviews involving non class members completed;
  - 262 Investigation Qualitative Reviews involving non class members completed;
  - 91 SRI for Hospitalization of non class members reviewed by our nurse;
  - 95 SRI Triage completed for *Evans* Court Monitor;
  - 46 Reviews of Recommendation reports completed for *Evans* Court Monitor.

METHODOLOGY

Most of the data analysis in this report is focused on the services and supports provided to non *Evans* class members who reside outside the family home. Our tool, and the manner in which we complete our work, is very 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. As has been the case over the past several years, our methodology remains unchanged: we create a statistically significant simple random sample. Over the course of the year, we meet non class members, interview them, and review the documentation found in their files in order to determine if they are receiving adequate services with appropriate results.

Additionally, Quality Trust's Monitoring unit receives reviews and analyzes incident management data for both class members and non class members. These sections reflect the results for everyone currently receiving services through the DC Developmental Disabilities Administration.

For our random sample: We continue to base our non *Evans* class member random review process on "Sampling, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs."[1] We have found this model to be an appropriate fit for our needs and plan to continue its use.

This year we requested and were provided 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 (211). 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 197 reviews of non *Evans* class members.

For our joint review with the *Evans* Court Monitor: The Judge in the *Evans* case required that the Department on Disability Services, the Court Monitor and Quality Trust develop a process for joint monitoring of compliance efforts required in order to conclude the case by August of 2012. Throughout the fall of 2010, and into the winter and spring of 2011, development of a joint tool was completed. Testing of that tool was conducted from April until June 2011. During the months of July, August, and September a piloting project was completed.

The methodology used for the pilot was to obtain a list of Evans class members who utilize Behavior Support Plans, and to draw a random sample of 10% (56 people) for whom we completed the Joint Monitoring Tool. The results of that work were included in the Court Monitor's October Quarterly Status report. Through our close participation in that process, we completed 40 Joint Monitoring Tools and participated in monthly meetings with staff from the Department on Disability Services and the Court Monitor.

DEMOGRAPHICS

Non Class Members Reviewed by Quality Trust

According to Developmental Disabilities Administration, there are now approximately 1526 non *Evans* class members receiving services and supports.[2] At any one time during the year, over 800 non class

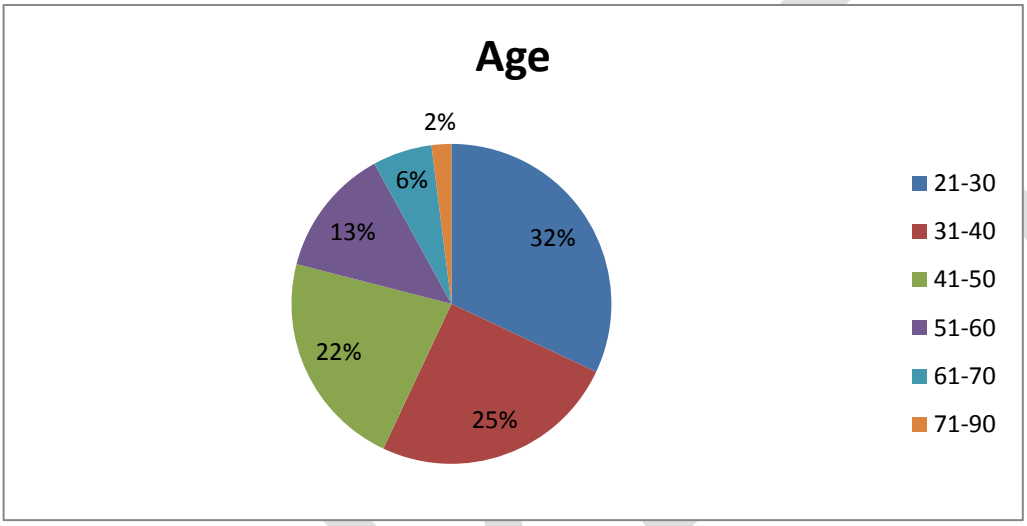
[1] Ruth Freedman & Sarah Taub, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs (Human Services Research Institute & Medstat Group, Inc. dev., National Quality Contractor 2006).h Institute & Medstat Group, Inc. dev., National Quality Contractor 2006).

[2] Elizabeth Jones, "Court Monitor's Report to the Court In the Matter of *Evans et al. v. Gray et al.*, Civil Action 76-293-ESH," at 6 (filed Aug. 3, 2011) (table entitled "Selected Fiscal Analysis of IDD Spending by the District from 2001-2011").

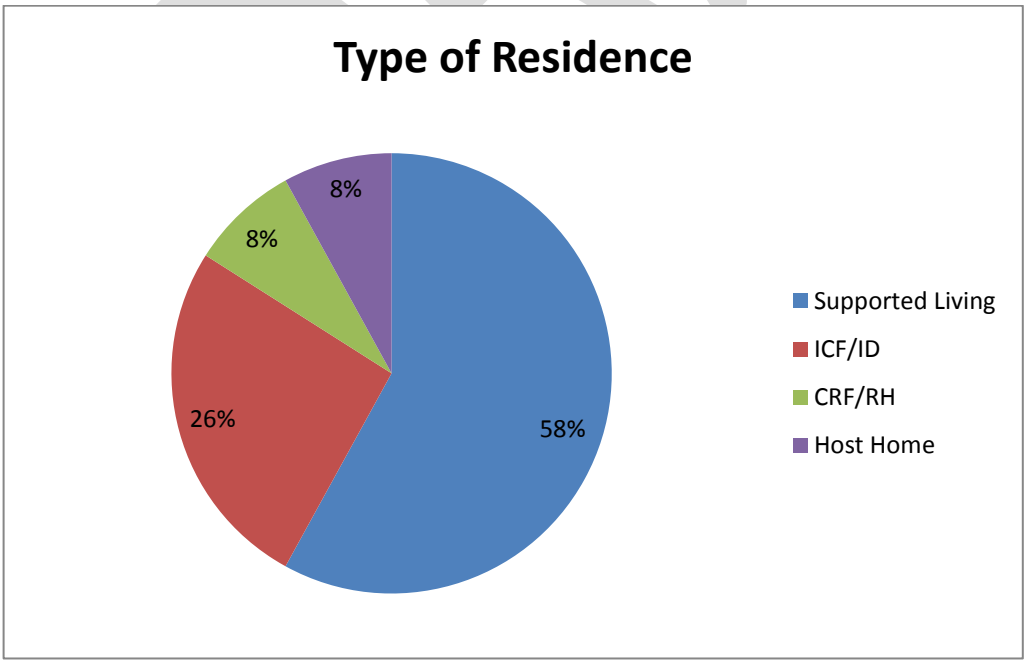
members live outside of the family home, and receive residential services. The data set we are studying is comprised of 532 people. We arrived at this number by reviewing the list provided by the Developmental Disabilities Administration, subtracting the 211 people we reviewed last year, subtracting the people living out of state, and subtracting the people who live on their own, with the assistance of little to no residential supports and services. From there, we generated a statistically significant random sample of 197 people to monitor. The information in this section regarding the 197 people included in the Quality Trust data set are broken down relative to age, diagnosis, type of residence, and source of funding and reflected below.

Age

80% of the people we met this year were between the ages of 21-50



Type of Residence



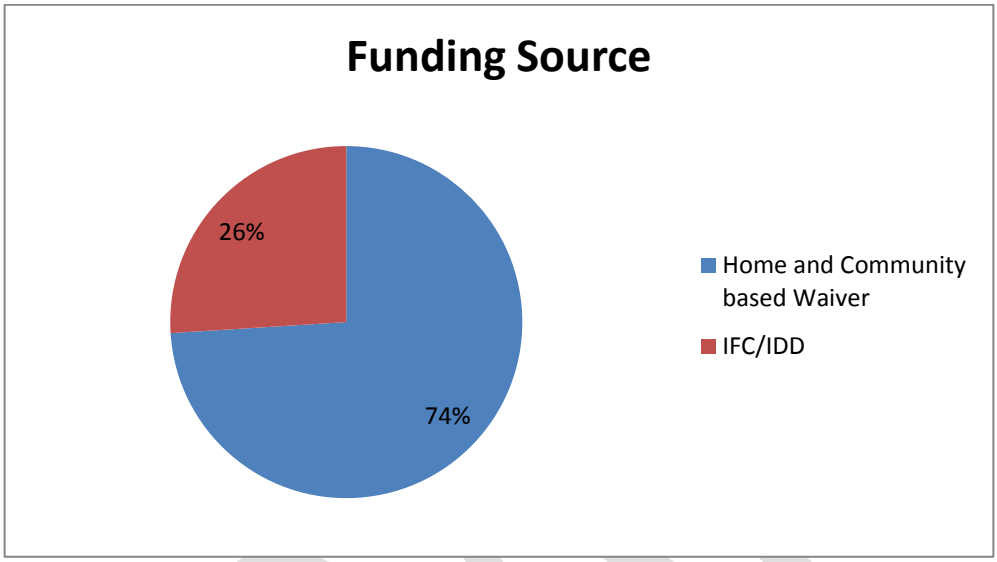
114 (58%) people lived in Supported Living, funded through the Home and Community Based Services Waiver

52 people (26%) lived in Intermediate Care Facilities for People with Developmental and other Intellectual Disabilities

The other 31 people (16%) lived in Residential Habilitation, and Host Homes - both services through the waiver

Funding Source

According to the proposed 2012 budget, Developmental Disabilities Administration projects that 1118 (73%) of non *Evans* class members of a total of 1526 people served will be supported on the waiver; however, not all of those people will receive out of the home residential services. For instance, some of the people on the waiver live at home and receive only case management, day program, transportation, and other clinical services as required. Overall placements for non class members in Intermediate Care Facilities are projected to be 185 of 1526 or (12%).[3] In our sample, the results were:



Conclusions

There are approximately 2100 people receiving supports funded through the Developmental Disabilities Administration. In 2001, when Quality Trust was created there were approximately 1600 people. (In 2001 the *Evans* class consisted of approximately 730 people, while the other 1270 people were non class members.) There are roughly 1526 non class members today, or just under the total number of people in services in 2001, while the number of *Evans* class members has dropped to approximately 566 individuals.[4]

In 2001, many more people lived in Intermediate Care Facilities for People with Intellectual and Developmental Disabilities, and/or large group homes of six people or more compared to today. Specifically, there were 224 people supported through the waiver in 2001, while 787 lived in Intermediate Care Facilities. Today there are 1469 people supported through the waiver and only 383 living in Intermediate Care Facilities.[5] Almost three quarters of the people we met lived in placements funded through the waiver, 114 of those people (58%) live in the least restrictive residential option available, Supported Living.

As we have commented in our previous reports, the vast majority of people we meet are young. This year almost 80% of the people we monitored were between the ages of 21-50. As we noted last year, the younger people entering the system have never been institutionalized and are looking for different kinds of services than those in prior generations. Providers will need to adapt their models of service delivery to this changing landscape if they hope to succeed in the system of the future.

[3] *See id.*
[4] *See id.*
[5] *See id.*

PERSONAL INTERVIEWS

Our monitoring procedure includes an interview with each person. We make every effort to honor the person's contribution to the review process through the personal interview. We begin each assessment by interviewing the person to ensure that his or her unique perspective is captured and included in the assessment results. Every attempt is made to elicit information directly from the person through as few filters as possible. At times, it is necessary to rely on those closest to the person to assist us with understanding the communication method and style of the person being reviewed.

The following information relating to choice and autonomy is derived from personal interviews of the people we met during our monitoring this year. These results reflect an *N* of 197 people.

- 151 (77%) People reported they had active family involved in their life;
- 138 (71%) people reported they had active friends (these relationships are usually between housemates);
- 65 (34%) people reported that they had friends without disabilities;
- 163 (84%) reported that were able to invite a family member or friend to their ISP meeting;
- 179 (92%) people reported that they liked their home;
- 142 (73%) reported that they have met their neighbor;
- 189 (97%) reported that they have privacy in their home when they need or want it;
- 122 (71%) report that they participate in their grocery shopping;
- 177 (92%) report that they participate in purchasing their clothes;
- 129 (66%) report that they participate in their personal banking;
- 141 (72%) report that they have their own bedroom.

Conclusions

We know that the struggle to live individualized and meaningful lives is vitally important to people with developmental disabilities. Outside of improving the provision of health and behavioral health services and supports, there is no more important undertaking than continuing to elevate the expectations of the professionals who support people receiving services and supports.

When compared to last year's results, this data reflects continued progress in creating more personalized services and supports. The increase in people reporting that they have active family in their lives and who reported that they had met their neighbors was particularly significant when compared with last year. The number of people who reported that they liked their home rose significantly over last year, as did the number of people who reported that they have privacy in their homes should they need or want it. These results seem to indicate a more person-centered approach and a change in the way people with disabilities are perceived.

We also hope and expect that improvements to the process of developing the ISP will aid in this process. DDA Service Coordinators have had time to adapt to the changes in ISP development ushered in 2008 with the development of the current Medicaid waiver. Goals and other supports outlined in the ISP should provide opportunities for people to learn about their options for community involvement and engagement.

INDIVIDUAL SUPPORT PLANS (ISPS)

Current ISPs

Of the 197 people reviewed 174 (88%) had a current, approved Individual Support Plan. This is a 10% increase from last year and a 9% 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. Our findings included the following:

- 154 (78%) contained measureable criteria by which the team could determine when the goal/outcome(s) had been achieved
- 129 (65.5%) contained goals reflecting the person's preferences and needs
- 128 (65%) contained supporting documentation which evaluates the provider's effectiveness in supporting the person to achieve their goals
- An area of weakness was the lack of pre planning meetings (44%)

In October 2008, DDA Service Coordinators assumed responsibility for developing ISPs for people they support. Since that time, the ISP document has been characterized as difficult to navigate and confusing. The DDA has worked to modify the ISP format and began use of a new version in October 2011 which contains changes to the lay-out aimed at making the document more accessible. DDA has made other changes as well. In August of 2011, DDA redistributed caseloads across Service Coordinators. There also have been a number of new training initiatives offered to Service Coordinators.

Conclusions

Our data this year indicates that the number of current ISPs has improved significantly. On the other hand, in some cases, the details of the plan are still lacking. This has occurred despite the fact that with Service Coordinators have had primary responsibility for developing the ISP since 2008. Service Coordinators have now had three full years to develop this skill. We hope that with the revised ISP format, new caseload distribution formula, additional training, and experience, Service Coordinators will gain the skills necessary to develop ISPs that more accurately and meaningfully reflect strategies, goals, and outcomes regarding establishing and expanding community involvement and relationships.

REVIEW OF HEALTHCARE

Health Management Care Plans, Medical Follow Up and Health Passports

One of the biggest challenges faced by many people we meet is access to high quality health and behavioral health services and supports. An essential prerequisite for good healthcare is a proper understanding of the person's health concerns, active management for those conditions, and effective coordination of services and supports necessary to ensure the person's optimum health. Therefore, as part of Quality Trust's health data collection protocol, our Monitors review medical records including determining whether a person has a Health Management Care Plan. Our findings this year indicate that there is progress with developing and implementing Health Management Care Plans for the people we reviewed.

- 163 people reviewed (85%) had a current Health Management Care Plan;
- 140 people (73%) had all of their follow up appointments or labs completed as scheduled;
- 177 people (90%) had a current Health Passport.

Analysis of 92 Serious Reportable Incidents of Non Class Members for Emergency Inpatient Hospitalization

Over the past three years, the number of people that are transported to the emergency room has been the single highest incident type in the District of Columbia. This year, for example, the number for both class and non class members combined was 372. Last year the number was 377. As we indicated in our report last year, we have been concerned about this trend.

Once our nurse joined our team in November of 2011, we began to look analytically at these incidents and their investigations. The question that we wanted to answer was: did these people use the emergency healthcare system because they lacked adequate care in their home, or was the visit to the emergency room unpreventable? We reviewed 92 of the 372 SRI's (25%) in an attempt to answer that question.

- A psychiatric emergency accounted for 24 of the 92 episodes (26%);[6]
- The other 68 SRI's (74%) involved some type of medical crisis;
- Additional training was recommended in 73 of 92 incidents (80%);
- In our opinion, the admissions were avoidable in 39 of 92 cases (42%).

In determining whether an admission was avoidable we looked for the following circumstances:

- The investigation indicated that the signs and symptoms were present for at least 48 hours prior to the visit;
- A pattern of similar incidents occurring previously was documented. This is especially true of bowel obstructions, and urinary tract infections;
- There was a lack of urgency in taking the person to their Primary Care Physician.

DDS had also been tracking this data and announced in October of 2011 that they were hiring a person in the Incident Management and Enforcement Unit to take a lead role in tracking this issue. A team within DDA has been formed to conduct further analysis of this issue.

Detailed Review of Health Care Provided to 35 Non Class Members

Our nurse completed a detailed review of the health and behavioral healthcare and nursing services provided to some of the people we met this year. This dataset WAS NOT randomly generated. For the most part her involvement with these people was initiated if they resided in an ICF/IDD, and/or if after one of our monitors met the person, they felt that the person had a moderate to complex set of medical and or behavioral health issues. The findings are mixed:

- For those people who had an order that their food intake be monitored, 66% had such documentation;
- For those people who had a need for their weight to be monitored, 67% had such documentation;
- Using the newly adopted Health & Wellness standards, 69% were receiving age and gender appropriate healthcare in a consistent and current manner;
- 74% of provider nurses monitored Health Care Management Plans at least quarterly;
- 94% had a current nutritional assessment;

[6] Prior to FY 2011, emergency visits of a psychiatric nature were categorized as 911-Criminal incidents. With the development of a new policy for the reporting and investigation of SRI's which took effect on October 1, 2010, medical and psychiatric emergency room visits were categorized as Emergency Inpatient Hospitalizations.

- 91% had physician ordered diagnostic consults completed within the recommended timeframe.

Conclusions

The data regarding the provision of health and behavioral healthcare and nursing supports at the provider level is mixed. We believe that the lack of evidence of adequate monitoring of food intake, and weight fluctuations is directly related to the number of Emergency Inpatient hospitalizations. An example from our experience will illustrate this conclusion: A person had been admitted to the hospital three times in as many months due to bowel obstructions and other elimination problems. There was no evidence that the provider's internal systems were tracking this, and, more importantly, putting into place remedies for it. To the contrary, the records indicated that after the third hospitalization, the Primary Care Physician (PCP) recommended a stool softener which was not administered by the agency nursing staff for almost six weeks. At the same time, the nursing staff did administer increased fiber but insufficient water. As a result the nursing staff was not remediating the problem, they were contributing to it. It is this type of failure that must be corrected without further delay for people to receive the kind of support that will enable them to live healthy and productive lives.

INCIDENTS AND INVESTIGATIONS

Quality Trust receives and reviews all Serious Reportable Incidents (SRI's) filed for class and non class members.

Beginning in FY 2011, the DDA revised its Incident Management Enforcement Unit (IMEU) policy regarding the manner in which Serious Reportable Incidents are generated, investigated, and categorized. The length of time given to providers to complete their investigations was increased, while the overall timeframe for closure remained constant. The policy also includes a method for grading provider investigations. Providers that demonstrate greater ability to produce timely investigations of sufficient quality receive less oversight, while those who struggle receive more.

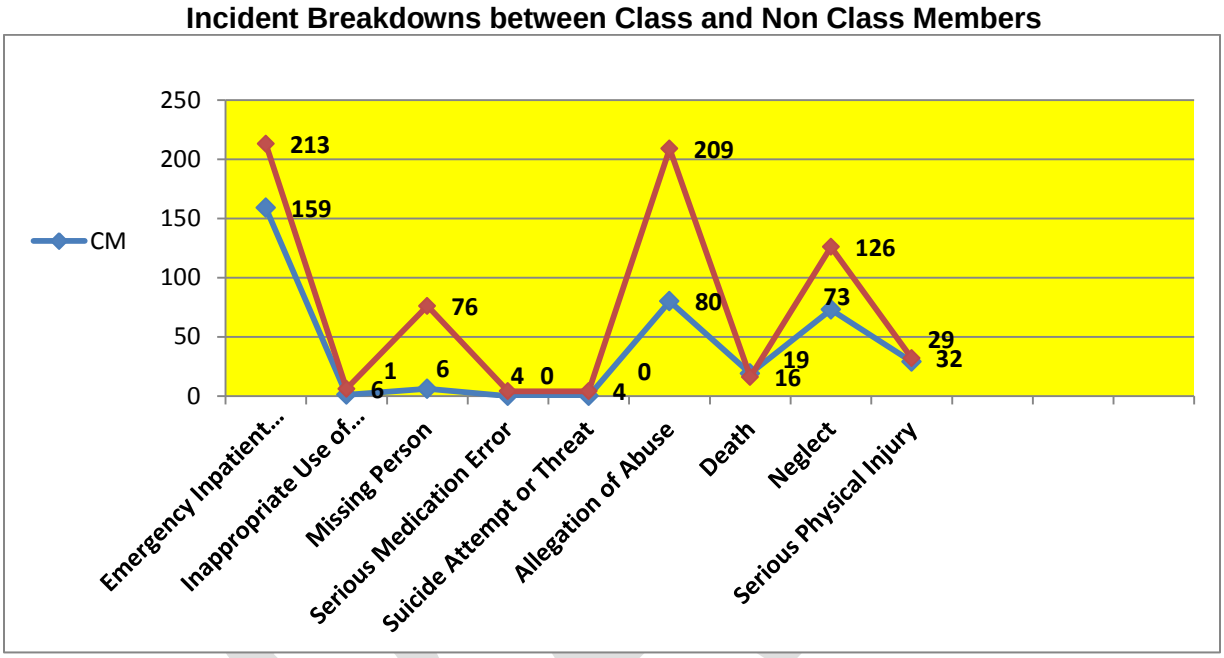
The ultimate goal of these changes was to place a different emphasis on the Incident Management Enforcement Unit investigators from primarily investigators of all incidents to providers of technical assistance for providers regarding the incidents of lesser seriousness, while maintaining their primarily role regarding investigations of more serious incidents. For the system to move forward, providers need to develop better analytical skills within their organizations; thereby, producing better investigations on their own. This, in turn, should allow Incident Management Enforcement Unit staff the opportunity to concentrate on taking the primary role investigating matters such as abuse, neglect and serious physical injury.

The data regarding the length of time required to investigate Serious Reportable Incidents shows remarkable progress. This is true for investigations of incidents involving *Evans* class members as well as non class members. As recently as two years ago, almost 50% of investigations were due and not yet complete by the end of FY 2009. This year that number is one (1) investigation.

Having addressed the issue of overdue investigations, there was concern at the beginning of this year regarding the quality of the investigations. There was steady improvement throughout FY 2011, but there still remain some challenges regarding timeliness accuracy and thoroughness in some of the reports. In October of 2011 DDA, IMEU leadership informed stakeholders of plans to hire another investigator (primarily to analyze Emergency Inpatient Hospitalizations), and to change the timeframe for completion of investigations from 45 business to 45 calendar days. A new Lead Investigatory was hired in January 2012.

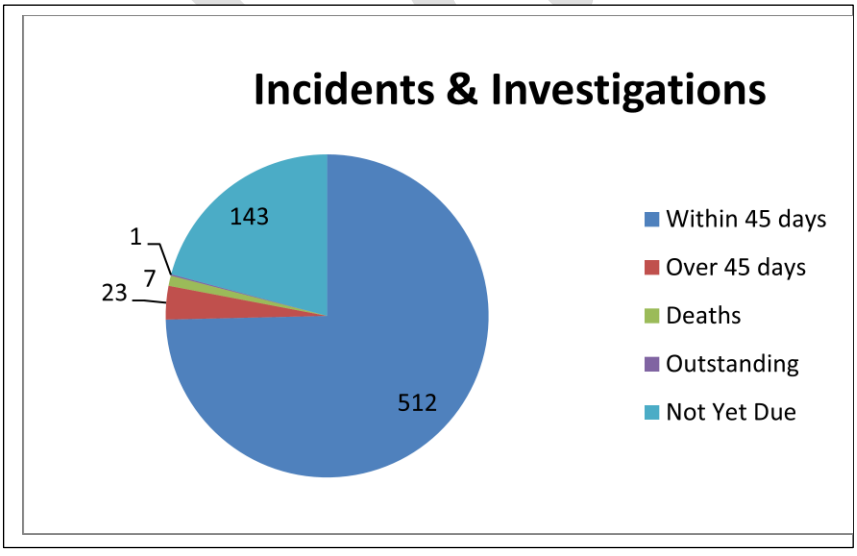
Serious Reportable Incidents

During the period from October 1, 2010 through September 30, 2011, 686 incidents were reported for non class members, which accounts for (65%) of the total of 1053 reported for people receiving services in the District of Columbia. We completed 442 triage reports, including tracking and trending analysis for these SRIs. There were 367 (35%) incidents were reported for Class Members. We completed 220 triage reports, including tracking and trending analysis regarding these SRIs and forwarded them to the Court Monitor.



Serious Reportable Incidents & Investigations

Quality Trust tracks investigations for all serious reportable incidents (SRI), 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, 2010 through September 30, 2011 (686 SRIs).



- 75% (512) of NCM investigations were completed within the 45 day timeframe
- 3% (23) of NCM investigations were not completed within the 45 day timeframe
- 21% (143) investigations were not yet due as of the last day of the fiscal year

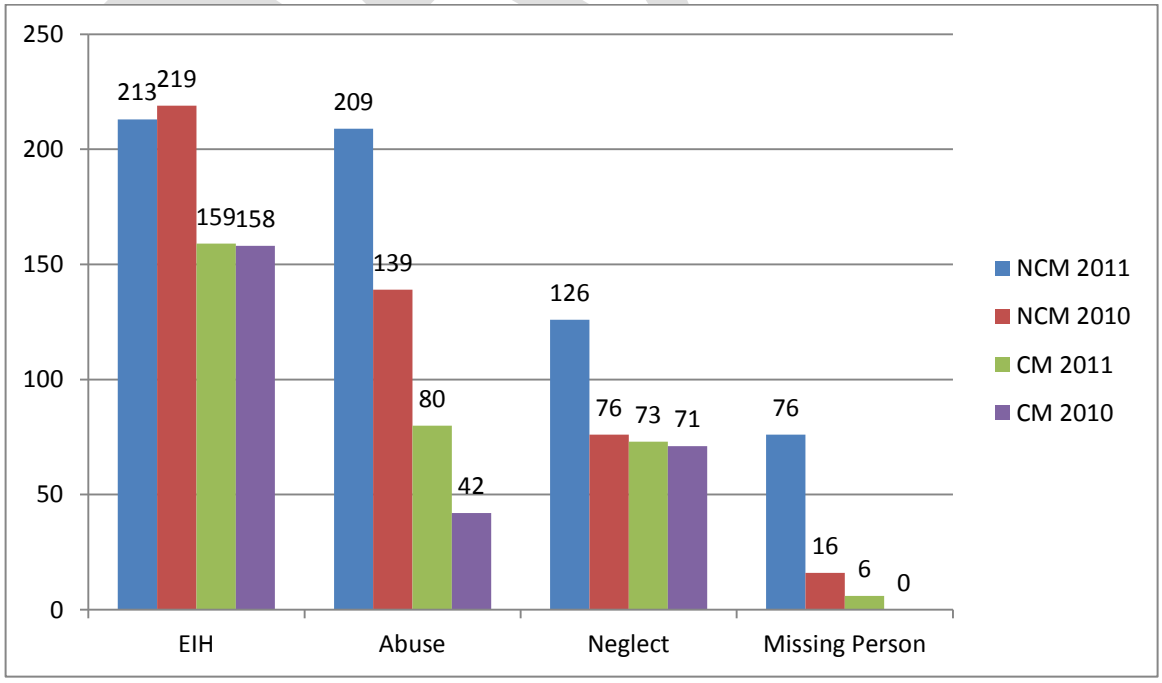
The chart below contains a comparison of incidents in FY 2010 and 2011 involving Evans Class Members and Non Evans Class Members.

Comparative Analysis of Incidents involving Class and Non Class Members

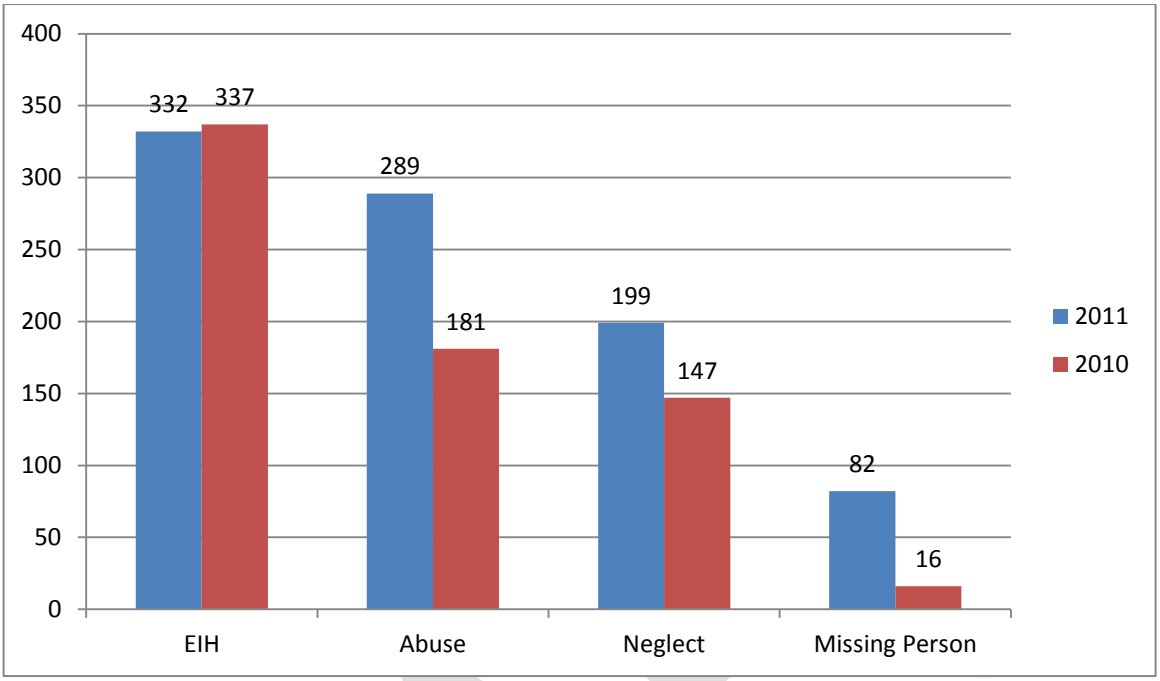
INCIDENT TYPE	NCM		CM	
	FY 10	FY 11	FY 10	FY 11
Emergency Inpatient Hospitalization	219	213	158	159
Inappropriate Use of Restraints	6	6	3	1
Missing Person	16	76	0	6
Serious Medication Error	4	4	2	0
Suicide Attempt or Threat	12	4	0	0
Allegation of Abuse	139	209	42	80
Death	17	16	16	19
Neglect	76	126	71	73
Serious Physical Injury	25	32	23	29
Theft	25	0	10	0

After falling back to 979 last year, the number of Serious Reportable Incidents increased to 1053. This number is similar to FY 2010 when the number was 1057. The increase was likely due to more training by DDA, IMEU and increased awareness of provider staff on what constitutes abuse and neglect.

Incident Comparison Non Class Members and Class Members
FY 2011 and FY 2010



Total Incident Comparison FY 2011 and FY 2010



- Once again, Emergency Inpatient Hospitalizations (EHI) remain the single highest incident type at 332;
- Allegations of Abuse rose significantly from 181 last year, to 289 this year;
- Neglect also increased from 118 incidents last year to 206 this year;
- The largest area of variation in results between class and non class members was in the Missing Person category; 76 NCM, and 16 CM;
- A small percentage of NCM 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 Serious Reportable Incidents involving non *Evans* class members we complete a triage form designed to help us both track and trend incidents, and provide us with a sense of what is happening for a person at a given time. The following is a summary of our findings in this area based on the 442 triage documents (42%) completed:

- We found evidence of Service Coordinator follow up regarding 63% of the SRI's;
- We found evidence that Service Coordinators completed the required 8 monitoring tools in 29% of the cases we reviewed;
- 42% of the people reviewed had at least one similar incident over the past year;
- Six people accounted for 12% (51) of the SRI's reviewed.

Qualitative Review of Investigations of Serious Reportable Incidents

Our qualitative look at investigations of Serious Reportable Incidents involving non *Evans* class members consisted of a review of 262 (25%) investigations, none of which were for Emergency Inpatient Hospitalization. We completed a separate review of those investigations, as discussed

above. We utilized the "Checklist for Reviewing Investigation Quality" which is based on the same tool used by Incident Management Enforcement Unit investigators per DDA policy.

Overall, the quality of the reports continued to improve from investigations completed as recently as two years ago. We also noted improvement throughout the year. Nonetheless, the data indicates that there is still a ways to go to reach the level of quality desired by people with disabilities, advocates, and the investigators themselves. Our review of the investigations found that:

- Just over 80% (209) of the investigations were completed in the timeframe set forth in policy;
- A site visit was completed in 88% (230) of the investigations;
- The site visit was completed within 24 hours in 68% (178) of the investigations;
- 91% of the investigations included documentation of an interview with the person;
- 63% contained evidence of a review of the alleged perpetrator's background information;
- 87% included evidence of a review of previous incidents involving the person; and
- 88% of the investigations contained an analysis of the information gathered to support the conclusion.

Conclusions

The total number of Serious Reportable Incidents recorded this year rose from last year. Increased training by the DDA and greater awareness at the provider level, especially of what constitutes abuse and neglect could account for the increase. Once again this year, Emergency Inpatient Hospitalization is the largest category of SRI. The quality of the investigations improved this year over last and significantly over the standard of two or three years ago.

We continue to have a significant concern with one specific change in policy which took effect in October of 2010. The policy mandates a site visit be completed by investigators within 24 hours of the date the SRI is received by the Incident management Enforcement Unit. As noted above, our review found that 68% of the investigations involving alleged abuse, neglect, and serious physical injury contained evidence that a site visit was completed within 24 hours by investigators. It is unclear to us from reviewing the investigations of abuse, neglect, and serious physical injury whether or not provider staff routinely make a site visit within a 24 hour timeframe; secure it and any evidence, if necessary. It is our understanding of the current policy is that Incident Management Enforcement Unit investigators are required to make a phone call to the provider within 24 hours of the day they are assigned the investigation. We believe this is a significant short coming of the current policy and recommend that a change be made to the policy requiring Incident Management Enforcement Unit investigators make a site visit within 24 hours of receiving the investigation.

Our findings with regard to the performance of Service Coordinators regarding completion of the required monitoring tools (29%) were disappointing. It should be noted that the policy regarding required completion of monitoring tools for non *Evans* class members changed toward the end of the fiscal year. Rather than require that eight tools be completed, the new policy requires only four, and only two for those non class members who live at home. It remains to be seen what effect this change has on provision of quality supports to these individuals.

Final Comments

Quality Trust was created in 2001 as part of the Evans case. Our mission has been to act as a catalyst to stimulate changes in the way services and supports are provided to people with developmental disabilities in the District of Columbia. That can only occur when people receiving services are viewed as valued people, with important needs and desires like any other person without disabilities.

Over the past ten years a great deal has changed. In certain key ways, the "system" of today bears little to no resemblance to that of 2001. Elevating the profile of people with developmental disabilities through the creation of the Department on Disabilities Services was an important step. So too was the creation of the current Home and Community Based Services (HCBS) waiver in 2007. Since 2001, spending on services and supports provided in the least restrictive setting has increased by over 10,000%.[7]in the District of Columbia through implementation of the revised waiver.

Our findings this year also indicate that the struggle to create meaningful change at the level of the individual person has begun to yield results. The increase in satisfaction indicated in our personal interviews is a hopeful development. Similarly, improvement in the findings relative to current ISPs and the completion of investigations of Serious Reportable Incidents are necessary improvements that have been a long time coming.

That said there is still much work ahead. Too many people lack adequate medical and behavioral health services. This is especially true for those people with moderate to complex health and behavioral health related needs. While improvements in residential services are noted, the same cannot be said of many of our day program providers. There are some positive exceptions, but most of the day programming available to people with developmental disabilities occurs in warehouses and other large segregated group settings.

This year, we witnessed the closure of a medium sized provider due to their inability to provide adequate nursing and medical services. The provider had been in operation for a number of years. In many cases, the Direct Support Professionals in the homes were caring people, but they lacked the knowledge and direction they needed to provide the necessary supports to people with moderate to complex health and behavioral health needs. In addition, there was a lack of timely and accurate information being shared between a primary care physician or psychiatrist and the provider nursing staff. This would seem to indicate a breakdown on the part of management functions at the provider level.

Throughout the thirty plus year history of the *Evans* case, advocacy for improvement in the lives of people with developmental disabilities has been a constant. But advocacy can only bring to light an urgent need and argue for resolution of that need. Government plays an important role in providing adequate funding for necessary services, as well as codifying through policy and law, the ground rules through which services and supports will be provided.

In August 2011, the Centers for Medicaid and Medicare Services (CMS) notified the District of Columbia that upon review it found deficiencies in 5 of the 6 basic assurances made by the District when it submitted the Home & Community Based Waiver that was approved in 2007. The District submitted a lengthy and detailed response. In October 2011, CMS responded with a final report which maintained the findings in the original draft. DDS and DHCF are working closely with CMS to address the concerns cited. The District must demonstrate an increased ability to collect and analyze data to drive its quality improvement activities as part of proceeding with the waiver renewal scheduled for this year. CMS also scheduled a fiscal audit of the waiver for January 2012. The results of this audit also will have an impact on development of the waiver application. CMS will be working closely with the District as the new application is developed.

At the same time, the District has been engaged in developing a new rate methodology for the ICF/IDD program. This process has been underway for almost two years, and the date for roll out is still in question. The interplay between the waiver and the ICF/IDD program is complex, so it is

[7] Jones, *supra* note 2, at 6.

important that the Department of Healthcare Finance (DHCF) and DDS partner successfully to ensure that rate structures for both programs are coordinated and complimentary. Both the new waiver application and the completion of the new rate methodology for the ICF/DD program must be successfully completed this year to ensure the stability of funding for services in the future.

The challenge continues to be ensuring that there are enough available providers with the capacity to deliver good quality services and supports operating in the District. This is important for ensuring there are a range of different services and skill sets available to provide adequate support to people and that people have some choice in picking from whom they get services. While DDA has clearly identified this as an issue, there is still work to do to reach this goal and some significant challenges that must be faced in the coming year to achieve that outcome.