



Quality Trust

for Individuals with Disabilities

Annual Monitoring Report And Data Summary

October 1, 2009 – September 30, 2010

Executive Summary

Quality Trust has expanded its monitoring activities this year in preparation for assuming responsibility for all monitoring when the *Evans* class action litigation is concluded. Enhancements were made in several key areas including tracking and trending of collected data and the addition of a full time nurse. Also for the past year, one of our Monitoring Specialists has been co-employed by the Court Monitor's office. This partnership has given us greater connection to and understanding of the work done by the Court Monitor. We continued to manage data on the timely completion and quality of investigations of Serious Reportable Incidents for both class and non class members. We continue to visit non class members living outside the family home in our randomly assigned review process, and when we feel a person may be at significant risk through our Serious Reportable Incident follow up process.

We participated in two collaborative projects this year; one with the *Evans* Court Monitor's office, the other with the Court Monitor, and DDS staff. In January 2010, we began a collaborative monitoring project with the *Evans* Court Monitor's office. The goal was to use the same survey instrument to review the services and supports provided to both class and non class members at a number of agencies. In this project, all non class members were reviewed rather than a selected sample. This project was completed in September 2010. In August 2010 the parties to the *Evans* case, now entering its thirty third year reached an agreement on a remedy. As a result the 2001 Plan for Compliance was updated to reflect progress made to date, and planning began for achieving compliance within a two year period on all remaining court orders. The implementation process will include joint monitoring between the *Evans* Court Monitor's office, Quality Trust, and Department on Disability Services. Throughout the summer the parties worked together to create a joint monitoring tool, interpretive guidelines, and training on the process. Joint monitoring team members were trained, and piloting was completed on December 13, 2010.

A few highlights of the data gathered over the last three years:

- **The number of current ISPs was 79% in FY 2008, 74% in FY 2009, and 78%, this year**
- **People receiving residential support funded through the Home and Community Based Services (HCBS) Waiver rose consistently from 54% in FY 2008, to 65% in FY 2009, to 73%, this year**
- **People who have a dual diagnosis remain relatively consistent, moving from 71% in FY 2008, to 72% in FY 2009, to 75%, this year**
- **In FY 2008 there were 664 SRIs, last year the number was 1057, and this year the total was 979**

Some highlights of our work this year include:

With the 211 randomly assigned assessments of non *Evans* class members living outside the family home completed this year, we have now completed 648 individual assessments over the past three years

An additional 47 assessments of non *Evans* class members were completed this year as part of our joint monitoring project with the *Evans* Court Monitor

979 Serious Reportable Incidents (both class and non class members) were cataloged into our database and analyzed relative to type of incident, class member status, and completion date

During the coming year we will add a more comprehensive Health and Wellness section to the tool we use in our randomly structured review of non *Evans* class members. This will give us a level of detail regarding the healthcare provided to non *Evans* class members we have not had in the past. With this and other additions we have made, our tool for FY 2011 is very similar to the one used by the *Evans* Court Monitor. Providers should benefit from the use of a single tool and process by both external monitors.

In addition to our ongoing monitoring activities, we are ready to participate in the joint monitoring if DDS should bring forth evidence of substantial compliance regarding the outstanding court orders from the newly update 2010 Plan for Compliance in the *Evans* case.

Methodology

For our random sample:

We utilize the sampling process outlined in “Sampling, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs”¹, a product of the National Quality Contractor for the Centers for Medicaid and Medicare Services (CMS). The booklet was developed by Human Services Research Institute, and The Medstat Group, Inc., and published in March of 2006. 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 (224). The resulting list consisted of 534 names. Our *N* for the sampling process was 534. It was our preference to set a 95% confidence level, and a confidence interval of 5%. Therefore it was necessary to complete 224 reviews. We fell just short of that goal, completing 211 reviews. 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.

For our joint review with the *Evans* Court Monitor:

We completed 47 additional reviews of non class members in our joint monitoring project with the *Evans* Court Monitor. We did not use a random sampling process for this project; instead we reviewed all non class members receiving services and supports from four provider agencies-Ebed, Center for Social Change, Westview, and MTS. Three of these providers were chosen because they had been reviewed by DDS through their Provider Readiness Process. These providers were chosen in January of 2010. In the spring of 2010, DDS began a new Provider Certification Process using Liberty Healthcare, a national contractor of quality assurance programs for state developmental disabilities agencies. Our work was completed between February of 2010 (Ebed), continuing on in March and April (Westview and Center for Social Change), and finishing up with MTS (June to August). In this project, our monitors completed all sections of the monitoring tool except the healthcare section which was completed by consultant nurses. This is the same model used by the Court Monitor’s office.

The data regarding the 211 randomly assess reviews are contained in this report. The results of our joint monitoring project are posted on our website, and available to anyone who would like to review them.

Updates to our Monitoring Tool

We have expanded our monitoring tool by including a day program review, and a service coordination review. Beginning in January of 2011 we will add the complete health section of the Joint Monitoring Tool agreed upon by the parties in the *Evans* case. Going forward our monitoring will mirror the process and tool used by the Court Monitor, and available to DDS. The method used will be exactly the same as the one described in our work with the Court Monitor.

The report is organized into the following six areas:

1. Demographics
2. Personal Interview
3. Individual Support Plans
4. Review of Healthcare
5. IMEU Data Analysis

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).

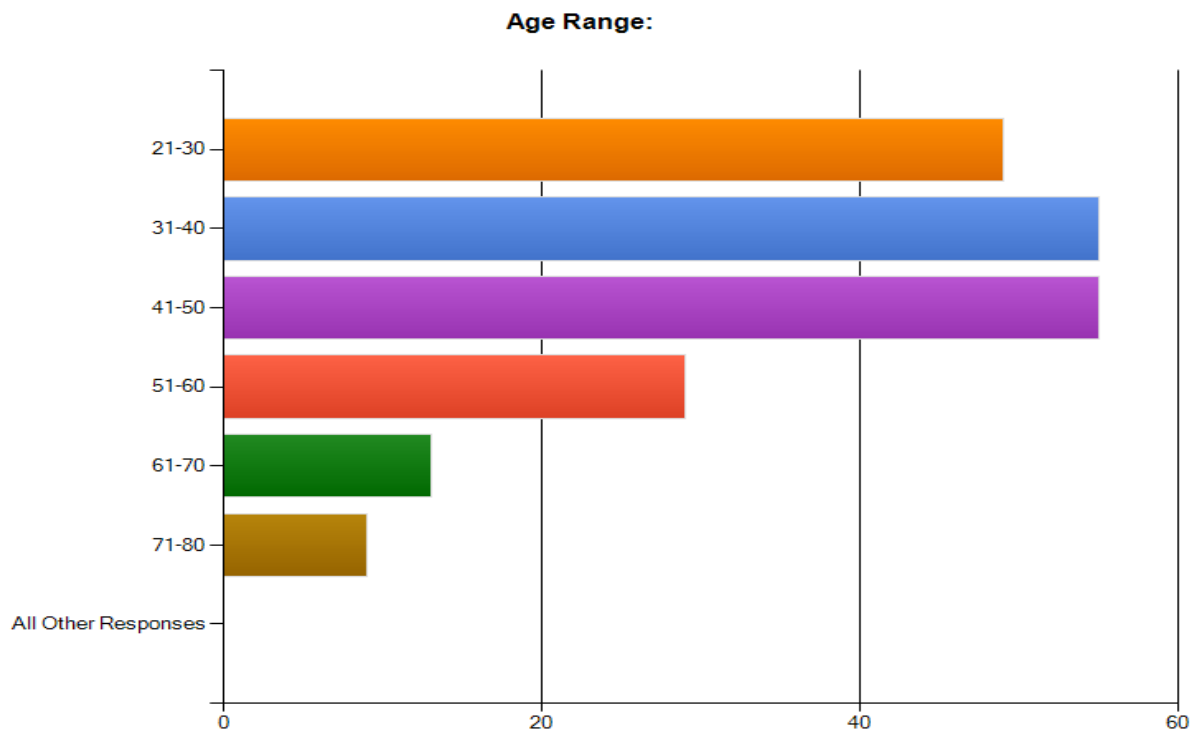
DEMOGRAPHICS

Non Class Members Reviewed by Quality Trust

According to the DDA, just over 800 non *Evans* Class members live outside of the family home, and receive residential services. The information in this section regarding the 211 people included in the random sample are broken down relative to age, diagnosis, type of residence, and source of funding and reflected below. All of these non *Evans* class members live in an out of the family home residential setting, and require supervision and/or other services and supports.

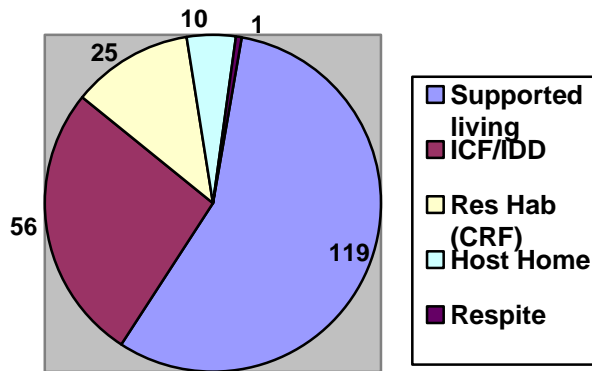
Age

- 55 People between the ages of 31-40 (26%)
- 55 between the ages of 41-50 (26%)
- The next largest group was 50 people between the ages of 21-30 (23%)
- 29 People were between the ages of 51-60 (14%)
- 13 People were between the ages of 61-70 (6%)
- 9 people were between the ages of 71-80 (5%)



Type of Residence

- 119 (56%) people lived in Supported living arrangements, a service funded through the Home & Community Based Services (HCBS)
- 56 people (26%) lived in homes certified as an Intermediate Care Facility for People with Intellectual and other Developmental Disabilities (ICF/IDD)
- 25 (12%) people lived in Community Residential Facilities/Residential Habilitation (CRF)
- 10 (5%) people lived in a Host Home
- 1 (1%) people lived in a respite setting

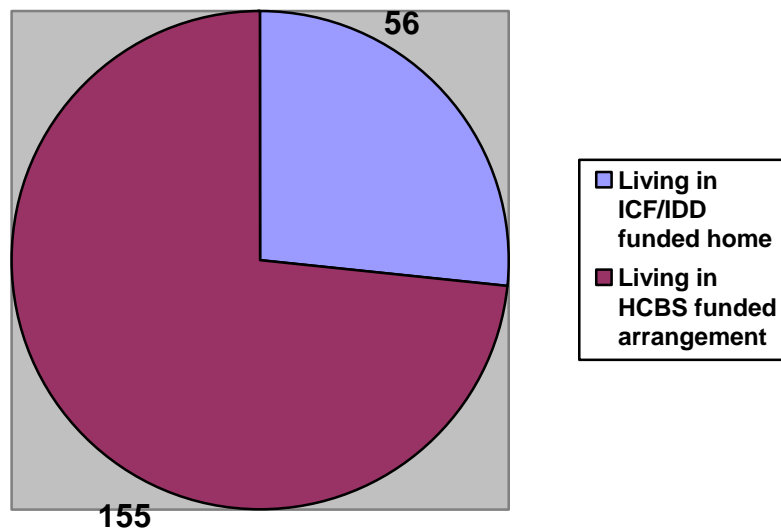


Types of Residence

Funding Source

- 155 people or (73%) live in placements funded through the HCBS waiver
- 56 people or (27%) live in institutional placements (ICF/IDD)

Residential Funding Source



Conclusions:

We have consistently found that non *Evans* class members are younger than class members and the data this year continues to confirm this conclusion. The trend of supporting non class members in services and supports funded through the HCBS waiver has also continued, and has actually increased when compared to our data from last year. Last year 65% of the people we reviewed lived in residences funded through the HCBS Waiver program, whereas this year the percentage is 73%. Additionally, last year 35% of the people we met were receiving their residential services in a home funded through the ICF/IDD program, whereas this year the percentage is 27%.

PERSONAL INTERVIEWS

Our monitoring procedure includes an interview with each person. We consider this interview to be the cornerstone of our process. 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 208 people, as 3 people declined to be interviewed.

- 129 (62%) people reported they had active family involved in their life
- 126 (61%) people reported they had active friends (these relationships are usually between housemates)
- 71 (34%) people reported that they had friends without disabilities
- 119 (57%) reported that were able to invite a family member or friend to their ISP meeting
- 146 (70%) people reported that they liked their home
- 108 (52%) reported that they have met their neighbor
- 147 (70%) reported that they have privacy in their home when they need or want it
- 120 (58%) report that they participate in their grocery shopping
- 138 (66%) report that they participate in purchasing their clothes
- 114 (55%) report that they participate in their personal banking
- 133 (64%) report that they have their own bedroom

Conclusions:

This data reflects progress in creating more personalized services and supports for the people we met, but the provision of supports and services that result in more meaningful lives for people has still yet to fully emerge. It remains our contention, and we believe this data confirms, that providers are missing opportunities to develop and expand integration into the communities where people live. It is important that providers improve their ability to support people in these elements that are essential for successful community living. We also hope and expect that improvements to the process of developing the ISP will be seen this year. According to accepted practice standards, DDS Service Coordinators should ensure that services and supports designed by providers are more meaningfully rooted in helping people develop the skills necessary to exercise greater autonomy and decision making. Supports should also identify specific opportunities for people to learn about the options for community involvement and engagement available to them. If this occurs, the numbers in this section will increase substantially.

INDIVIDUAL SUPPORT PLANS (ISP)

Current ISP's:

- Of the 211 people reviewed 164 (78%) had a current, DDS approved ISP. This is a 4% increase from last year, but still less than the 79% we found in our 2008 report.

In October 2008 DDA Service Coordinators assumed responsibility for developing ISP's for people they support. The ISP document used throughout most of FY 2010 was viewed by many providers and external monitors as problematic for several different reasons. DDA modified the document and the new version began to be used in September of 2010. We hope that with the new document, and another years worth of experience and training, Service Coordinators will develop ISPs that more accurately and meaningfully reflect strategies, goals, and outcomes regarding establishing and expanding community involvement and relationships.

- 106 (51%) of the ISPs reflected the person's preferences and needs and contained a community integration strategy plan and/or goals.
- 128 (61%) of the ISPs did not identify barriers that would limit the achievement of goals or outcomes
- Provider documentation evaluating their effectiveness in supporting people to achieve the goals and outcomes continues to be a concern. 91 of 211 (43%) ISPs had supporting documentation. This is consistent with our findings last year (43%), reflecting no progress made in this area.
- We found an increase in the number of plans that described the staff support necessary for the achievement of goals and outcomes. Last year 48% of [plans contained this element, while this year the percentage rose to 56%. While it is always good to see progress, unfortunately, 56% means that only slightly over half of the plans contain such descriptions.

Conclusions:

The percentage of current ISPs continues to hover around the 78% mark for the third year. There was wide agreement that changes were needed to make the plans clearer, and to add items such as financial information. Another change has been in the area of documenting unmet needs from the previous year. This should help Service Coordinators and providers focus their efforts on obtaining the services and supports needed but not yet provided; not only throughout the year, but also from year to year. Obtaining and analyzing this data is a valuable tool for quality improvement. As this data shows, providers must continue to make improvements in how they provide services and supports. Overall, we do not see the accurate and detailed person centered plans essential to ensure sustained and marked improvement in the day to day lives of people with developmental disabilities.

REVIEW OF HEALTHCARE

Potential Health Risk Assessment:

Quality Trust uses a standardized checklist to identify health conditions that when present can increase the risk of serious health problems. A point value is assigned for the presence of each specific health concern, event or significant changes in behavior. We know that as a group, non *Evans* class members are younger, and less medically complex than a many people in the *Evans* class. We use this tool to identify trends or patterns in specific types of diagnoses or conditions. We also use it in concert with other tools to help us

evaluate if a person is receiving the proper health supports. In the past we would refer the person to either the Health or Wellness Unit of DDS or the Health Resources Partnership project through Georgetown University if we were concerned that a person was not receiving the services he or she needed. With the addition of a full time nurse, we now have the ability to make a full assessment of any concerns or findings we have relative to the health and behavioral healthcare services and supports being provided.

Between October 1, 2009 and September 30, 2010 we identified several areas of note from our review of the health status, services and supports of the people we visited. The *N* for data in this section is 175 people, as 36 people had no conditions, or took no medications that would trigger at least one of the indicators. Listed below are the most prevalent conditions and or concerns we found this year:

- The single largest indicator was the use of psychotropic medications. 116 of 175 people (66%) who had at least one indicator were prescribed at least one psychotropic medication.
- Hypertension, 59 people (33%)
- Use of neuroleptic medications, 46 people (26%). Again, use of these medications is not a negative finding by itself, but we do know that some people who do not have documented seizure activity are prescribed these medications, possibly for their sedation effect. Additionally, both psychotropic and neuroleptic medications are commonly used in conjunction for people with psychiatric diagnoses.
- Major seizure disorder 35 people, (20%)
- Bowel elimination problems, 27 people (15%)
- Diabetes, 18 people (10%)

Over the past three years we have monitored approximately 650 people who are not members of the *Evans* class. During that time we have identified the need to develop a data gathering process that looks at the relationship between the activities and lifestyle patterns of the people we meet, and health related diagnoses and conditions. With the addition of a full time nurse, we are working to design such a process. We will share our initial findings in our report next year.

Some of the areas of concerns are:

- Side effects of psychotropic/neuroleptic medications
- Obesity
- Poor nutrition
- Lack of exercise
- Proper follow through on recommended protocols (for mealtimes, personal hygiene, assistance with positioning and movement, etc.)

Health Management Care Plans:

As part of the QT health data collection protocol, QT Monitors review medical records including whether a person has a Health Management Care Plan. 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. Our findings this year indicate that there is progress with developing and implementing Health Management Care Plans for the people we reviewed.

- 181 of the 211 people reviewed (86%) had a Health Management Care Plan
- 166 of the 211 HMCPs (79%) contained evidence they were monitored

- 71% of the HMCPs were monitored either monthly (43%) or quarterly (28%)
- A provider nurse was the predominant monitor of the HMCP for 181 of 211 (87%)
- 132 people or (64%) had all of their follow up appointments or labs completed as scheduled

Behavior Support Plans

Data was also collected for people who had a behavior support plan recommended. If a person is taking psychotropic medication it is the DDS policy that they also have a Behavior Support Plan. We also monitor the DDS policy and provider practice regarding implementation of Behavior Support Plans through our participation in the Restrictive Controls Review Committee (RCRC). Policy and practice changes regarding the documented use of psychotropic medications for people with a Behavior Support Plan are also addressed in this venue. It is our understanding that the DDS is currently in the process of developing new guidelines on both of these issues, and will be taking the new policy forward in the near future.

Findings for this year include:

- 104 of the 211 individuals reviewed (49%) had a behavior support plan implemented, of those:
 - 53% contained target behaviors consistent with the diagnosis
 - 33% had data collected correctly
 - 35% demonstrated a review of data by the psychologist or psychiatrist
 - 39% contained procedures used to address behaviors consistent with BSP and DDS policy
 - 45% of BSPs contained no documentation of approval by DDA's RCRC

Dual Diagnosis

Dual Diagnosis is a term applied to people who have a diagnosis of a co-existing intellectual or developmental disabilities and mental health issues. The *N* for this question was 207 because we had 4 instances where we could not definitively determine the presence of an Axis I diagnosis due to poor documentation, such as "CFSA transfer, or unknown, or no Axis I diagnosis available."

- 159 of the 207 people (75%) had a co-occurring Axis I and Axis II diagnosis (dual diagnoses) indicating the presence of a mental health condition in addition to their intellectual disability.

This percentage is higher than other national statistical benchmarks we have found. It is important to note however that our data set is comprised solely of non *Evans* class members who live outside the family home. It is not uncommon for such a group to have significantly more complex needs, when compared with people who remain at home with their families. In many cases, the need for increased support is what resulted in people leaving the family home. Some national data support this conclusion by showing that higher percentages of people with co-occurring diagnoses (both medical and behavioral health) live outside the family home. At the same time, many of these same studies addressing the prevalence of dual diagnosis include both people living at home with family as well as people living out of home in supported living settings making direct comparisons with our data difficult.

We have looked for additional data that might explain our findings being higher than other reported statistics. One report published in July 2007 by Charlie Lakin, Ph.D., et al., at the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota offers some

interesting insights to consider.² This study looked exclusively at people receiving Medicaid Home and Community based and ICF/ID residential services in six states. The study was based on a large, random, multi-state sample of nearly 3,000 community and institutional service recipients with intellectual disability. The overall percentage of co-occurring diagnosis in all states was 31.4%. While we have consistently found a higher percentage in our sample (71% in FY 2008, 72% in FY 2009, and 75% FY 2010) over the past three years, the DDS reports 38% of all people funded through the DDA have an Axis I Diagnosis, which is only slightly higher than the average reflected in this national study. In general, we would expect the overall number to be lower than ours because of the number of people supported by the DDA live at home with family who might therefore have less significant rates of mental and physical health needs. The DDA supports approximately 670 people (32%) at home with family and 1435 (68%) outside the family home.

According to the Lakin study, the percentage of psychiatric diagnosis tends to be higher in people whose intellectual disability is less significant. For people whose Intellectual disability was characterized as mild, the percentage of co-occurring diagnosis was 39%. For people with a diagnosis in the moderate range, the percentage was 32%. For people characterized as profoundly disabled the percentage reduced to 16%. As we have noted in this and our previous reports, the people we review tend to be younger, physically healthy, and many have diagnoses in the mild or moderate range of intellectual disability. We also speculate that a number of people who enter the DDS system through the child welfare system might be at higher risk of emotional concerns because of problems with family and in home supports, though we have not located research on this specific factor.

Another notable finding in the Lakin study is that among people receiving an Axis I diagnosis, about 87% received one or more psychotropic medication for behavior, anxiety or mood stability compared to 32% of people with only an intellectual disability. Our data this year indicate that 118 people (57%) were prescribed a psychotropic medication. This is lower than in the Lakin study.

Young people often come into the DDS system with diagnoses made during their school years, or in the child welfare system. The DDS is tasked with getting to know these people and determining if the diagnoses that accompany them are valid. The DDS has worked over the past two years to increase the number of psychologists who have experience working with people with intellectual disabilities to increase the quality of diagnostic and treatment services. This is an important initiative needed to improve supports over the long term. In the short term, the DDS is revising its policy and practices governing the implementation of Behavior Support Plans, as well as practices governing the use of psychotropic medications.

The Lakin study concludes, "There is a high prevalence of mental health needs for individuals with intellectual disability who receive waiver services." DDS has effectively transitioned a significant number of people from the ICF/IDD model, to services and supports funded through the HCBS waiver. It is reasonable to project that the non *Evans* class members reviewed in our report are representative of the people who will be supported by the DC system in the future with HCBS Waiver services. Therefore, we believe further examination of the factors leading to the increased prevalence of mental health (Axis 1) diagnoses for people with intellectual disability in DC is an important dynamic to understand and address going forward.

² Charlie K. Lakin et al., "Adults with Dual Diagnosis of Intellectual and Psychiatric Disability Receiving Medicaid Home and Community Based Services (HCBS) and ICF/MR Recipients in Six States," (Mental Health Aspects of Developmental Disabilities, 2007), available at: <http://www.thefreelibrary.com/Adults+with+dual+diagnoses+of+intellectual+and+psychiatric+disability...-a0168354677>.

Medication Use

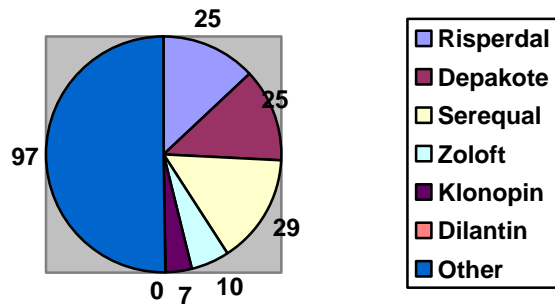
Psychotropic medications:

Information regarding psychotropic and neuroleptic medications was collected and reviewed with specific emphasis given to identifying people taking more than one medication for a single condition (poly pharmacy). Poly pharmacy is not necessarily contraindicated, but we know all too well that poor communication between different prescribing doctors can result in situations in which people are taking several medications without adequate consideration given to the potential for negative outcomes. Further, the use of many medications for diagnosed mental health conditions are of specific concern because of the potential for long term debilitating side effects. We also monitor current the DDS policy and provider practice regarding use of psychoactive medications in relation to implementation of Behavior Support Plans through our participation in the Restrictive Controls Review Committee (RCRC). Policy and practice changes regarding the documented use of psychotropic medications for people with a Behavior Support Plan are also addressed in this venue. It is our understanding that DDS is currently in the process of developing new guidelines on both of these issues, and will be implementing the revised policy in the near future.

- 118 (57%) people were prescribed a psychotropic medication
- 36 (17%) people are taking 1 psychotropic medication
- 43 (21%) people are taking 2 psychotropic medications
- 41 (19%) people are taking 3 or more psychotropic medications
- 20 (17%) people were taking psychotropic medications without a BSP which is a conflict with DDS policy
- 62 (53%) people did not have documentation of approval by the provider Human Rights Committee

Detailed information on the medications prescribed was collected for the people taking medication within the 228 people in the data set. This included data on the specific psychotropic and neuroleptic medications prescribed. The most common medications were:

- 25 (21%) took Risperdal®
- 25 (21%) took Depakote®
- 29 (25%) took Serequel®
- 10 (8%) took Zolof®
- 7 (6%) took Klonopin®
- 0 (0%) took Dilantin®
- 97 (82%) took one of several other drugs such as Zyprexa, Luvox, Wellbutrin, Lexapro, etc.



We want to clarify our position on the use of these medications. Some who read our report last year interpreted our comments as advocating against the use of such medications. Quality Trust supports the use of psychotropic medications for people with psychiatric diagnoses when medication is determined to be the best treatment option. In many cases, the use of these medications enables people to experience relief from debilitating symptoms such as pervasive and/or overwhelming sadness, fear and anxiety, hallucinations, etc. Medications can be an important part of an overall treatment plan. We also recognize and acknowledge that there are significant risks associated with the long term use of psychoactive medications. As such, other treatment methodologies should be considered and use of medications should be minimized as much as possible. This approach is consistent with accepted standards of practice.

We seek to highlight several findings in our reporting. First, as stated earlier, we have consistently found a larger percentage of people than is “typical” with developmental disabilities in DC have also been diagnosed with mental illness. Many people who take psychotropic medications take two or more, and for some of those people they do so in the absence of meaningful positive behavior supports as an alternative. We believe that in many instances there may be an overreliance on or a “medication first” approach to treatment. We further believe that a great deal more can be done regarding making appropriate psychiatric diagnoses for people with intellectual disabilities in the District of Columbia. Finally, we believe that when these medications are used, more thought should be given to how many medications are used and for what purposes. Several people we have met over the years have been taking one or more psychotropic medication for several years without an analysis of the benefit and effectiveness of reduction or elimination of some of the medications. Our experience with the psychiatrist on the Restrictive Control and Review Committee has given us great insight into the issues described above.

Conclusions:

Our data this year is strikingly similar to that found in both of our previous reports. The typical non class member described as being reasonably healthy and likely to have significant mental health issues is supported by our current data. As will be reported in the next section, use of the 911 system for emergency room visits was drastically reduced from last year, but the incidence of emergency inpatient hospitalizations continues to be very high. We cannot offer a definitive explanation for this outcome. We do know from both our analysis on Serious Reportable Incidents and our work with the joint monitoring work with the *Evans* Court Monitor, that recurring urinary track infections and bowel impaction continue to account for a number of these hospitalizations. Another possible explanation could be that some SRIs involved people being transported to the hospital for emergency psychiatric admissions, so a portion of these numbers might reflect psychiatric rather than medical emergencies. It is also possible that these increases reflect the fact that people are not accessing proper healthcare early enough, so the situation rises to the level of requiring an emergency trip to the hospital. With the addition of our full time nurse, and the addition of a more robust health review section to our tool, we hope to have a more definitive answer on this question in next year’s report.

A dual diagnosis was noted for three quarters of the people we reviewed. As we noted last year, this is nearly double the national rate. We question whether this finding is related to the limited number of psychiatrists who have experience working with people with developmental disabilities in the District of Columbia. We also note that there are many improvements needed in the area of behavior support planning – especially in the use of positive approaches that will assist people to develop new and more adaptive strategies for coping with stresses and life challenges. Both of these factors make access to high quality behavioral health supports a challenge. Work continues to increase the number and skills of psychiatrists willing and able to treat people with intellectual and other developmental disabilities.

INCIDENTS AND INVESTIGATIONS

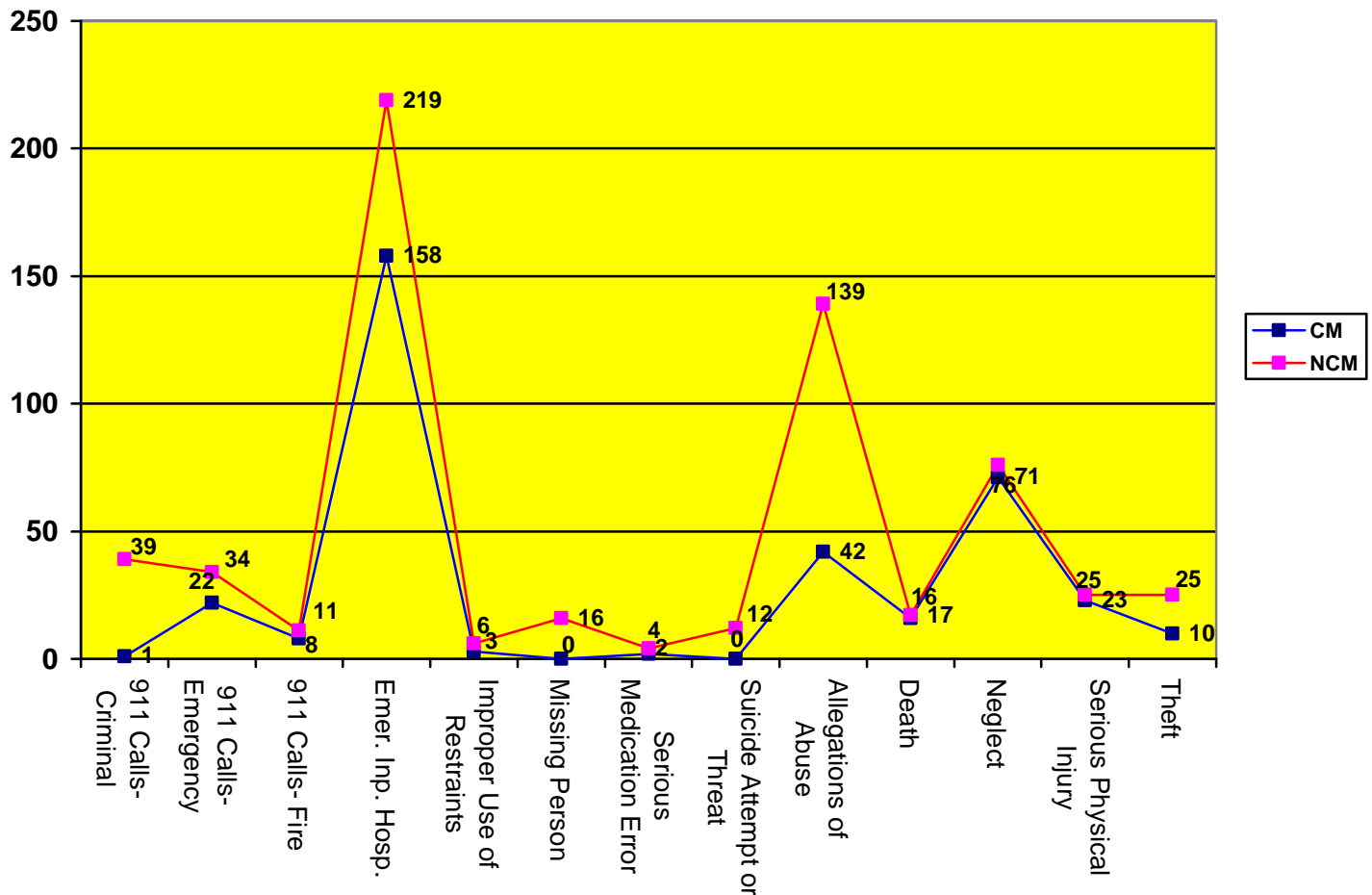
Quality Trust receives all Serious Reportable Incidents (SRI's) filed for class and non class members. In the past, data on the number and type of incidents reported was reviewed and reconciled monthly with staff from the Department on Disabilities Services (DDS); Developmental Disabilities Administration (DDA) Incident Management Enforcement Unit (IMEU). We called this process reconciliation. Over the course of the past year, the DDA discontinued staff involvement in this process relying instead on the exchange of electronic data. We have continued to collect and track the data we receive from DDA, IMEU using the process established several years ago. We believe this process is important, and ensures that the information received by Quality Trust matches what has been reported to and received at the DDA. We also track the completion and timeliness of required investigations of incidents. Data is summarized quarterly and shared with the Court Monitor for review and feedback. We have also made this information available to DDA.

The process for tracking and reporting information on incidents and investigation used by Quality Trust was jointly developed with the DDA based on shared understanding of expectations and policy. We have worked hard to keep an open and cooperative working relationship around this process. Over the past two years, the DDA has been developing a new policy for the reporting and investigation of Serious Reportable Incidents. The policy became official on October 1, 2010. The new policy retains the overall timeframes for the completion of investigations of Serious Reportable Incidents, but several other categories of information within our data base need to be updated to match the new categories. We are currently updating our database so that it exactly matches all timeframes, categories, and definitions described in the new policy. The data reflected in this report is based on the processes previously agreed to by the DDA, IMEU.

Serious Reportable Incidents:

During the period of October 1, 2009 through September 30, 2010, 623 incidents were reported for non class members, which accounts for (64%) of the total of 979 reported for people receiving services in the District of Columbia. We completed 560 of our triage reports, including tracking and trending analysis for these SRIs. 356 (36%) incidents were reported for Class Members. We completed 220 of our SRI triage reports, including tracking and trending analysis regarding these SRIs and forwarded them to the Court Monitor.

Incident Breakdowns between Class and Non Class Members



Investigation of Serious Reportable Incidents:

Quality Trust tracks investigations for all serious reportable incidents, 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, 2009 through September 30, 2010 (623 Serious Reportable Incidents).

Serious Reportable Incidents & investigations

- 31% (157) of the NCM investigations received by QT, which were due by September 30, 2010, were investigated within the 45 day timeframe.
- 69% (352) of the NCM investigations received by QT were not completed within the 45 day timeframe.
- There were 59 NCM investigations due, which were not yet been received by QT as of the end of FY 2010. 27% (16) of those due but not received are level 1 incidents, requiring a full investigation by IMEU policy.
- As of 9/30/10 there were 55 investigations not yet due.

The chart below contains a comparison of both level 1 and level 2 incidents in FY 2009 and 2010.

Comparative Analysis of Level 1 & 2 Incidents involving class and non class members, FY 2009-2010

INCIDENT TYPE	NCM		CM	
	FY 09	FY 10	FY 09	FY 10
<i>911 Calls- Criminal</i>	57	39	8	1
<i>911 Calls- Emergency</i>	182	34	130	22
<i>911 Calls- Fire</i>	5	11	1	8
<i>Emergency Inpatient Hospitalization</i>	144	219	124	158
<i>Improper Use of Restraints</i>	6	6	1	3
<i>Missing Person</i>	13	16	4	0
<i>Serious Medication Error</i>	2	4	1	2
<i>Suicide Attempt or Threat</i>	22	12	2	0
<i>Allegation of Abuse</i>	140	139	42	42
<i>Death</i>	10	17	19	16
<i>Neglect</i>	37	76	40	71
<i>Serious Physical Injury</i>	21	25	22	23
<i>Theft</i>	17	25	7	10

Comparison of Investigations Received involving Class and non Class members FY 2010

INCIDENT TYPE	NCM FY 10		CM FY 10	
	# Of Incidents Reported	# Of Investigations Due But Not Received by QT	# Of Incidents Reported	# Of Investigations Due But Not Received by QT
<i>911 Calls- Criminal</i>	39	8	1	0
<i>911 Calls- Emergency</i>	34	17	22	11
<i>911 Calls- Fire</i>	11	2	8	1
<i>Emergency Inpatient Hospitalization</i>	219	4	158	1
<i>Improper Use of Restraints</i>	6	1	3	0
<i>Missing Person</i>	16	7	0	0
<i>Serious Medication Error</i>	4	1	2	1
<i>Suicide Attempt or Threat</i>	12	3	0	0
<i>Allegation of Abuse</i>	139	1	42	0
<i>Death</i>	17	13	16	10
<i>Neglect</i>	76	0	71	2
<i>Serious Physical Injury</i>	25	2	23	3
<i>Theft</i>	25	0	10	0

Level 2 Incidents involving non Class members

- 911 Criminal incidents decreased from 57 incidents to 39
- 911 Emergency decreased significantly from 182 incidents 34
- Emergency Inpatient hospitalization increased significantly from 144 to 219
- Also increasing was Missing Persons, which increased from 13 incidents to 16
- Improper use of restraints remained consistent in FY10, at 6 incidents

Level 1 Incidents involving non Class members

- Allegations of Abuse decreased slightly from 140 to 139
- Neglect allegations increased significantly from 37 to 76
- Serious physical injury increased from 21 to 25
- Theft increased from 17 to 25

Closure of overdue investigations for FY 2009

In our report last year, we noted that 498 of the investigations due by the end of the fiscal year had not been received. During the course of FY 2010, 460 of these investigations were closed by DDA. As we were performing our reconciliation efforts between April and July of 2010, we noted that we had not received investigations for 271 of the closed investigations. We made DDA aware of this fact, and we were informed that due to a miscommunication between the Deputy Director and the senior staff within the IMEU, no IMEU reviewed investigations had been completed for those 271 incidents. It was reported by the DDA in November 2010 that an additional 75 investigations were not assigned to an investigator. According to our analysis the number was 77 unassigned investigations. The breakdown over fiscal years is: 19 from FY 2009, 57, from FY 2010, and 1 from FY 2011. That brings the total number of investigations from FY 2009 which were not directly investigated by IMEU or closed after a review of the provider investigation to 290. DDA has been working to collect provider investigations for all of these incidents. As of December 13, 2010, we have received primarily provider investigations for 256, leaving 34 of the initial 290 investigations due, but not yet received for FY 2009. In addition, there are four other investigations due but not yet received from FY 2009. Therefore, as of December 13, 2010, there are 38 investigations due but not yet received for FY 2009.

Qualitative Review of Incident Investigations

Qualitative reviews of investigations of Serious Reportable Incidents involving non class members were completed using the “Checklist for Reviewing Investigation Reports for Comprehensiveness and Quality,” tool. This tool is designed to track data collected in the course of an investigation, and the time frames required to complete investigations. We analyzed the investigations relative to the documents reviewed by investigators during their investigations, interviews conducted of witnesses, victims, and people involved, any other evidence gathered during this process. All Quality Trust monitors have successfully completed the DDS investigation training, passed the exam, and are certified.

Our Monitoring Specialist who is co-funded with the Court Monitor’s office completed 108 follow up reports involving recommendations made in investigations involving class members and forwarded them to the Court Monitor. These follow up reports seek to obtain documentation that recommendations made in investigations were in fact fully implemented.

We completed 101 qualitative reviews of investigations involving non class members. These IMEU investigations asked the correct investigatory question, but many were completed long after the incident which limited their effectiveness. This was especially true regarding making timely recommendations for incidents that occurred in the past. Although our analysis indicates that the vast majority of investigations reviewed were completed after the 45 day time frame, we did notice a reduction in the number of days overdue as the year progressed.

- 22 (22%) investigations were completed within the 45 day time frame
- 79 (78%) investigations were completed after the 45 day time frame

We also reviewed 210 (82%) of the 271 provider only investigations from 2009

- 97 (46%) were completed within the 5 day time frame
- 199 (49%) were not completed within the 5 day time frame
- 11 (5%) were unsigned or dated so we could not determine the answer

There was significant variance in the overall quality of the provider investigations. Many failed to ask the correct investigatory question (e.g., why did a person require a trip to the emergency room or were staff negligent by failing to protect a consumer's possessions). Instead they focused on whether the provider followed its procedure for a given emergency. There was also a lack of uniformity in the manner in which the investigations were conducted, and in the veracity of the documentation contained in the investigations.

When we identify what appears to be a practice which is in conflict with policy, or when we need clarification on practice, we dialog with IMEU or QA staff in order to get clarification. We have had dialog with the Chief of Quality Assurance regarding the issue of provider reports not being on file well after the required timeframe, and he has assured us that the new policy and practices will address this issue, as well as the timely completion of investigations.

Conclusions:

There was a reduction in the number of Serious Reportable Incidents filed this year. Last year there were a total of 1057 SRI's, while this year there were 979, a decrease of 78. The biggest area of increase occurred in the category of Neglect. Last year there 77 SRI's in the Neglect, whereas this year there were 147, an increase of 70. Whereas last year there were 312 SRI's in the category of 911 Emergency, and this year the number was 56, a substantial decrease of 256.

It is the DDA policy that investigations of SRI's be completed in 45 business days. Quality Trust received 282 level 1 Serious Reportable Incidents (abuse, neglect, death, serious physical injury, and theft) involving non *Evans* Class members covering the period 10/1/09 through 9/30/10. All level 1 SRI's require a full investigation. As of September 30, 2010, 16 (6%) of those investigations involving non class members were not received by Quality Trust. We also note that 13 of those were deaths, so we do not expect an investigation from IMEU as death investigations are completed by an external contractor. Of the remaining three investigations, 2 involved serious physical injury, and 1 was an allegation of abuse.

There was a dramatic increase in the number of investigations completed in FY 2010. The rate of completion of investigations of SRIs for non class members was 34% in FY 2008, 27% in FY 2009, and rose dramatically to 90% this year. The Chief of Quality Management is confident that the new policy and practices which officially began on October 1, 2010 regarding the reporting and investigation of Serious Reportable Incidents will enable IMEU to close more investigations within the required timeframes, and that investigations will be of good quality. The new process involves review of all provider investigations by IMEU staff. Providers will be graded on the content of the investigations, and DDA will be tracking the implementation of recommendations made. The policy stipulates that providers who can not demonstrate an ability to produce satisfactory investigations will receive direct intervention from DDS. Providers who continue to struggle will face a number of potential consequences during their certification review or renewal. Given the great variance in the quality of provider reports we reviewed this year, it is essential that the review process be vigorous, and transparent. It is equally important that providers who are unable to produce satisfactory investigations are quickly identified. Remediation efforts must quickly follow, and effective intervention implemented to ensure the health and well being of people supported.

From our review of investigations completed in FY 2010, we believe that much work is still needed to ensure that investigations are not only completed within the required timeframes, but are also of reasonable quality.

FINAL COMMENTS AND SUMMARY

It is clear from our data and personal observations that there is slow but steady improvement in changing the manner in which services and supports are provided on behalf of people with developmental disabilities in the District of Columbia. Most of the data gathered over the past three years indicates that through the implementation of new and revised policies and practices, gains in some specific areas are being made. Overall however, indicators have remained consistent and stable. The data in this report does indicate significant progress in two areas: 1) shifting away from the ICF/IDD as a residential living model to the more individualized HCBS waiver funded services, and 2) the completion of investigations for Serious Reportable Incidents.

There are still significant challenges ahead in order to achieve the kind of outcomes for people with developmental disabilities desired by all. It is our contention though that minds and hearts of many people must change first, and then actions will follow. DDA has implemented a values based training initiative designed to emphasize the importance of listening to and supporting the people receiving services. We are beginning to notice the dialog changing from one centered on what is not possible for the people we meet to one centered on new opportunities and possibilities for people receiving services and supports. It is this type of change which gives us confidence that the kinds of data tracked in our report will improve over the next year.

Improvements for people with developmental disabilities require efforts from people beyond the scope of the DDS. The DC City Council has continued work on new legislation and the outdated law governing how services are organized and delivered might be replaced by a new one sometime in the coming year. While the relationship between the DDA as the implementing agency and the Department of Healthcare Finance as the Single State agency responsible for implementation of the HCBS waiver is working well, the partnership between the DDA and the Health Regulatory and Licensing Administration remains problematic.

Two of the most significant challenges in the short term are the inevitable impacts of budget cuts, and the continued need to challenge providers to embrace the changes needed in order to improve the quality of services and supports to people. The HCBS waiver budget was already cut by 3% for FY 2011 and there is an additional cut of \$3.5 million dollars proposed for implementation this budget year. Any cuts to residential services will likely disrupt the movement away from the large medical model living arrangements (ICF/DD) abandoned as a primary model in the rest of the country decades ago.

Money is only one part of the equation however. It is essential going forward that overall standards for practice and expectations for service outcomes must be raised. Minimum performance should ensure health, safety and access to community activities for people receiving services. Increased internal provider quality assurance capacity is needed; particularly the positive and negative impacts of services and supports provided for people. More progress is needed in perfecting analytical capabilities, so that problems identified can be more quickly addressed and corrected. There is ample assistance available for those providers ready to embrace that type of change. Retention of qualified providers and dismissal of those unable to demonstrate consistently acceptable practice must be the shared outcome of government; be that DDS, the Department of healthcare Finance, or the Health Regularity and Licensing Administration.