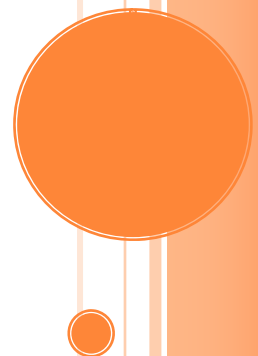


Quality Trust for Individuals with Disabilities Monitoring Unit Annual Report and Data Summary

October 1, 2008 – September 30, 2009



Executive Summary

The results of our monitoring activities this year lead us to the conclusion that progress in improving the system of services and supports for people with developmental disabilities in the District of Columbia is mixed. Improvements have been made in several key areas, while serious flaws still hamper higher levels of quality and consistency in supports and services. Greater attention to the coordination and execution of healthcare and behavioral healthcare is needed at the provider level. A more consistent and transparent process for investigating Serious Reportable Incidents at DDA is also necessary. Without improvement in these key areas, the health, safety and well being of people with developmental disabilities receiving services and supports in the District of Columbia will continue to be in question.

On the positive side, we found and our data confirms:

- More of the non Evans Class members we met are leaving institutional placements in favor of those funded through the HCBS waiver. The Money Follows The Person initiative is the primary vehicle for this expansion. Last year 45% lived in ICF's/IDD, whereas this year the number is 35%. Living arrangements funded through the HCBS waiver were increased from 54% to 65%.
- As the pace of this process picks up, DDA, led by its Service Coordinators is becoming more successful leading teams in offering real choices regarding the types of supports received
- Service Coordinators have begun to assume responsibility for developing the ISP
- A new DD law has been drafted and was introduced by the City Council in October. A hearing on this is scheduled for December
- Through Mayoral Order in June 2009 a new Inter-agency taskforce was created placing the Deputy Director of DDA at the head of much of the decision making around services and supports regardless of where the person lives or the types of services received
- Better coordination between DDA and The Department of Health Care Financing, is giving the Deputy Director of DDA greater control over administrative and fiscal policy for services and supports in the HCBS waiver

In spite of progress noted above, the following significant flaws still remain:

- We are aware from reports of the Evans Court Monitor that many providers are unable to guarantee the provision of effective, well coordinated health services and supports for too many Evans Class members. We have seen similar short comings in the healthcare provided to some of the non Evans Class members we monitored
- Far too many people we met are administered medications with potentially serious side effects; in fact 135 people were found to be taking more than one psychotropic or neuroleptic medication with 16 people taking three or more psychotropic medications
- Many of those same people have a Behavior Support Plan. In a many cases evidence of approval from DDA's Restrictive Control Review Committee to use both the medications and the BSP's was not present in the person's file
- While coordination between DDA and DHCF has improved, the relationship between DDA and the Health Regulation and Licensing Administration (HRLA) is still evolving. This disconnect, evident in the recent situation regarding appropriate sanctioning of a certain provider for inadequate coordination and execution of healthcare services poses significant problems for people living in ICF's/IDD

Our biggest concern is the failure of the IMEU (Incident Management & Enforcement Unit) of DDA to complete investigations of Serious Reportable Incidents (SRI's) in the timeframe required by DDA policy. Our data indicates that investigation reports are not being completed consistent with policy (there were 404 SRI investigations due, for non Evans Class members but not yet received as of September 30, 2009), and we are beginning to see a bifurcated system as relates to completion of investigations for Evans Class members compared to others in the system. Investigations for 87 allegations of abuse, and 23 for neglect involving non Evans Class members were due but not received by Quality Trust as of September 30, 2009. There were only 8 such investigations in each of those categories involving Evans Class members not received. Statistics for many other categories of Serious Reportable Incidents yield the same results.

METHODOLOGY

The process used to complete our monitoring assessments underwent a change beginning in July of 2009. Historically there were two components of the process: visiting as many different locations as possible (i.e. ICF's/DD, apartments, CRF's, etc), and then randomly selecting the people who would be monitored. Until this year we were unable to get a reliable accounting of all non Evans Class members who lived outside of the family home and received what are typically thought of as "residential services". Lacking that key information, the approach focused on viewing as many different types of services and facilities within each provider, and then introducing random selection. While this approach was less than fully desirable from a scientific basis, we were able to mitigate those effects given the large numbers of monitoring assessments we were able to complete. Last year for instance we monitored 212 people, and this year the number was 228.

Three factors influenced our decision to begin piloting a new process in July of 2009: We wanted to conduct the most scientifically rigorous approach possible; we wanted to begin our preparation for the day when the Evans case is closed, and we will remain as the single independent monitoring entity in the District of Columbia; and with the possible adoption of a new law governing the make-up of the DD "system" in the future, we anticipate monitoring many more people than we current do. All of these factors led us to adopt an approach that would give us the most scientifically rigorous model in which the results of relatively few assessments yields the most accurate information about the lives of people within the system.

Once we had full, accurate data on all non Evans Class members living outside the family home who are receiving residential services, we adopted the model outlined in "Sampling, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs"¹, a product of the National Quality Contractor. The booklet was developed by Human Services Research Institute, and The Medstat Group, Inc., and published in March of 2006. The booklet was an initiative of the Centers for Medicare and Medicaid Services (CMS) as technical assistance for states confronting the issue of how to construct large samples of recipients of supports and services funded through HCBS waivers. Given our resources, and the group we anticipate eventually monitoring we decided their approach was an appropriate fit.

We also used this opportunity to revamp our monitoring tool; reviewing other tools, and adding several questions from the tool used by the Court Monitor in the Evans case. We converted our new tool to a web based approach, giving our monitors the ability to complete their work in real time "in the field".

Finally, beginning in October of 2009 we began a partnership with the Evans Court Monitor in which we are sharing the services of a Quality Trust monitor. This is another effort to begin the transition to the day when the Evans case is closed and we remain as the single independent monitoring entity in the District of Columbia.

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).

DEMOGRAPHICS

Non Class Members Reviewed by Quality Trust

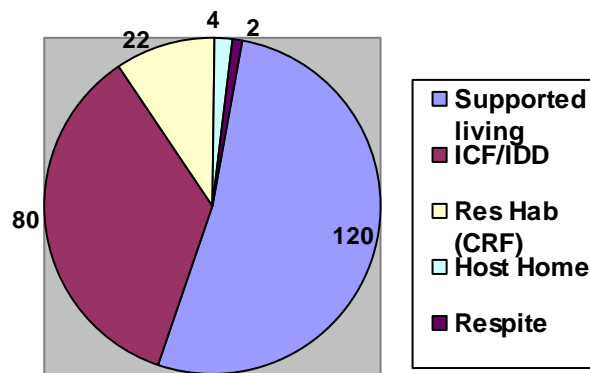
According to DDA, approximately 790 non Evans Class members live outside of the family home, and receive residential services. The information in this section regarding the 228 people included in the QT data set are broken down relative to age, diagnosis, type of residence, and source of funding and reflected below. By definition then all people reviewed in our report live in some sort of out of the family home residential setting. The data set we are studying is comprised of approximately 535 people. We arrived at this number by reviewing the list of 790 supplied to us by DDA, subtracting the 212 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.

Age

- The highest percentage of people (32%) or 74 people are between that ages of 40-49.
- 63 (27%) are between 30-39
- 52 (23%) are 29 and under
- 39 (18%) are age 50 and over (Interestingly, 2 people we met were between the ages of 70-79 but did not live at Forest Haven)

Type of Residence

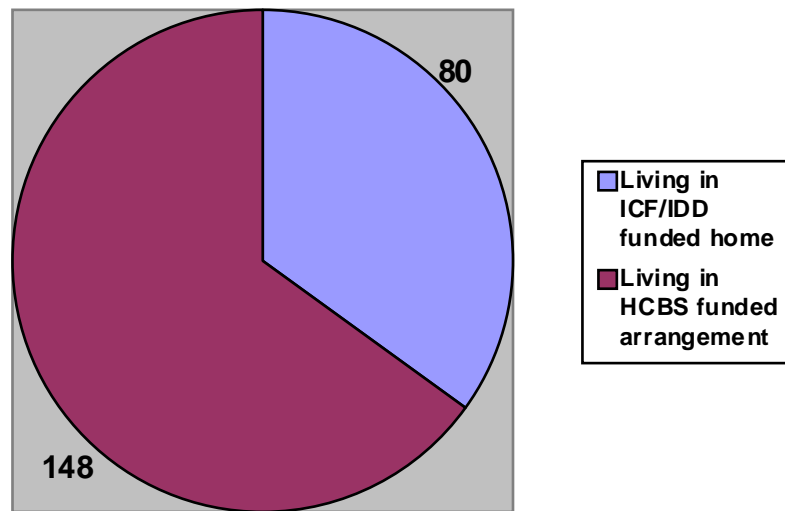
- 120 people (53%) live in Supported living arrangements, a service funded through the HCBS waiver.
- 80 people (35%) lived in a home certified as an Intermediate Care Facility for People with Intellectual and other Developmental Disabilities (ICF/IDD)
- 22 people (10%) live in Community Residential Facilities/Residential Habilitation (CRF), a waiver service
- The other 6 people (2%) either were in Respite or Host Home, a new service funded through the waiver



Types of Residence

Funding Source

- 80 people or (35%) live in institutional placements (ICF/IDD)
- 148 people or (65%) live in placements funded through the HCBS waiver



Residential Funding Source

Conclusions:

As we noted last year, non Evans Class members are younger than members of the Evans Class. Using the Money Follows the Person Demonstration Grant, DDA has achieved substantial results “rebalancing” the current arrangement away from placements in the ICF/IDD program to the HCBS waiver program. This is a positive development for which leadership at DDA and The Office of Chronic and Long Term Care Services within the Department of Health Care Financing deserve praise.

PERSONAL INTERVIEWS

Our monitoring procedure includes an interview with each person. We consider this interview to be the cornerstone of the process. We begin each assessment by interviewing the person to ensure that this 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 style of the person. The following information relating to choice and autonomy is derived from personal interviews of the people we met during our monitoring this year.

- 15 (7%) people reported choosing their own doctor
- 14 (6%) people reported choosing their own dentist
- 62 (27%) people reported that they had friends without disabilities
- 106 (46%) reported that they have met their neighbors
- 135 (59%) reported that they participate in a group or organization
- 135 (59%) participate in their own grocery shopping
- 178 (78%) participate in buying their own clothing
- 160 (70%) report having their own bedroom
- 98 (43%) report that they answer the door when the doorbell rings
- 104 (46%) report that they have a key to their home
- 70 (31%) report using public transportation

Conclusions:

This data reflects small gains in some areas from last year, but overall the results remain disappointingly low. It is clear from this data that providers are missing countless chances to develop and increase people's opportunities for greater integration into the communities in which they live. As we said in our report last year, this is the very premise on which the HCBS waiver is based. Our hope for the coming year is that providers improve their ability to support people in these essential elements of community living. We also hope and expect that Service Coordinators will become more insistent (through the development of the ISP) that the services and supports designed by providers are more meaningfully rooted in developing the skills necessary for people to enjoy more opportunities to make choices and exercise autonomy over their lives.

INDIVIDUAL SUPPORT PLANS (ISP)

Current ISP:

- Of the 228 people reviewed 169 (74%) had a current, DDS approved ISP. This is a 5% decline from last year.

In October 2008 DDA Service Coordinators assumed responsibility for developing a person's ISP. Our findings this year indicate a reduction in the number of current ISP's from 79% to 74%. We had hoped that with Service Coordinators developing the plans, we would see more accurate and meaningful strategies, goals, and outcomes regarding establishing and expanding community relationships, but that was not the case. For instance:

- Last year 8% of the ISPs contained a community integration strategy plan and/or goals. This year we found that 6% of the ISPs contained documentation of this type of planning
- Therefore, 92% of the ISP's we reviewed lacked documentation of the planning necessary to increase the numbers cited above
- There was improvement in documentation of the staff support necessary for meaningful community integration activities. Last year we found 42% of the plans had this type of documentation this year the number was 48%. Nevertheless, a little over half of the plans did not indicate an understanding by providers of the staff commitment necessary for creating greater community presence of the people they support

Conclusions:

Regarding the reduction in the number of current ISPs, it is possible that the newness of the expectation was overwhelming to some Service Coordinators. Regarding the content of the plans, we observed that many seemed to contain similar language and information as the previous year, when the plan was developed by third party contractors. Overall, we have yet to see the kind of accurate and detailed person centered plans one would expect to see from advocacy based Service Coordinators. We hope that next year we see marked improvement in the development of ISPs.

REVIEW OF HEALTHCARE

Potential Health Risk Assessment:

Quality Trust uses a standardized checklist to identify conditions observed in people with intellectual and other developmental disabilities that can increase their risk of health problems. A point value is assigned for the presence of specific health concerns and significant changes in behavior. We are able to access the services of a Consultant Nurse. The QT Nurse Consultant is certified through the Developmental Disabilities Nurses Association (DDNA). In past years we arranged for our nurse to visit with people to conduct a review of their health status and care using the standards established through the DDNA. In those occasions, a report is prepared and shared with people supporting the person. More recently when we encountered people with significant identified health risks we make referrals to the Health Resources Partnership consultants (DCHRP) from Georgetown University.

- Between October 1, 2008 and September 30, 2009 we identified several areas of note from our review of the health status, services and supports of the 228 people we visited. As we have noted earlier in our report with the widespread use of psychotropic medications, the risk of side effects is increased. As a result we worked with the QT consultant nurse to enhance our understanding of the proper protocol governing the use of psychotropic medications; particularly in understanding the known negative effects of using more than one of these drugs at any one time.

Listed below are the most prevalent conditions and or concerns we found this year:

- Major seizure disorders 26 (11%)
- Bowel elimination problems 12 (5%)
- Diabetes 11 (5%)
- Hypertension 26 (11%)
- Use of psychotropic/neuroleptic medications 162 (71%)

Since we have now monitored significant numbers of non Evans class members (approximately 440 assessments in the past two years), we will enhance our tool to further focus on the issues we have come to know are present in the people we meet and can adversely impact health. Some of these 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.)

Our Follow up on Serious Reportable Incidents (SRI)

In addition to performing our 228 monitoring assessments, we reviewed all 1057 SRI's generated this year. There was a significant increase in the number of SRI's in the categories of 911 Emergency (transportation of a person to the emergency room-many times by ambulance), and Emergency Inpatient Hospitalization. The number of these SRI's rose for both Class and non Class members. Taken together there were 327 SRI's for non Class members in these two categories. In the late summer we began performing basic tracking and trending analysis with data available to us to determine if patterns of poor provider performance, and/or significant health issues were driving these increases.

The fact that over 300 SRI's involving transportation to a hospital, and/or admission to a hospital is concerning. We are not yet able to offer a definitive conclusion about this trend, but we are looking into at least two possibilities. It is possible that some of these people are receiving emergency healthcare because they did not receive proper routine services. It is also possible that some of these visits occurred because staff became overwhelmed with a given situation, called the doctor who in turn requested that the person be taken to the hospital for follow up. We will continue to perform tracking and trending analysis of these categories of SRI, and with more data hope to better understand the reasons for their occurrence.

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 provision of high quality health and behavioral health services and supports. One essential element to providing good healthcare is properly understanding the person's health concerns, managing those conditions, and coordinating the services and supports necessary to ensure the person's optimum health. We found this year that the providers have done a good job of developing Health Management Care Plans for the non class members reviewed.

- Of the 228 people reviewed 210 (92%) had a Health Management Care Plan.

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 DDS policy that they also have a Behavior Support Plan. Through our participation in the Restrictive Controls Review Committee (RCRC) we became more aware of current DDS policy and provider practice regarding implementation of Behavior Support Plans by providers, so we added several questions to our tool which will help us understand provider compliance with proper development and implementation of the BSP.

- 145 (64%) of the 228 individuals reviewed had a behavior support plan implemented.

Of 39 people monitored with additional questions added to our tool, these are our findings relative to BSP's:

- 56% contained target behaviors consistent with the diagnosis
- 35% had data collected correctly
- 38% demonstrated a review of data by the psychologist or psychiatrist
- 41% contained procedures used to address behaviors consistent with BSP and DDS policy

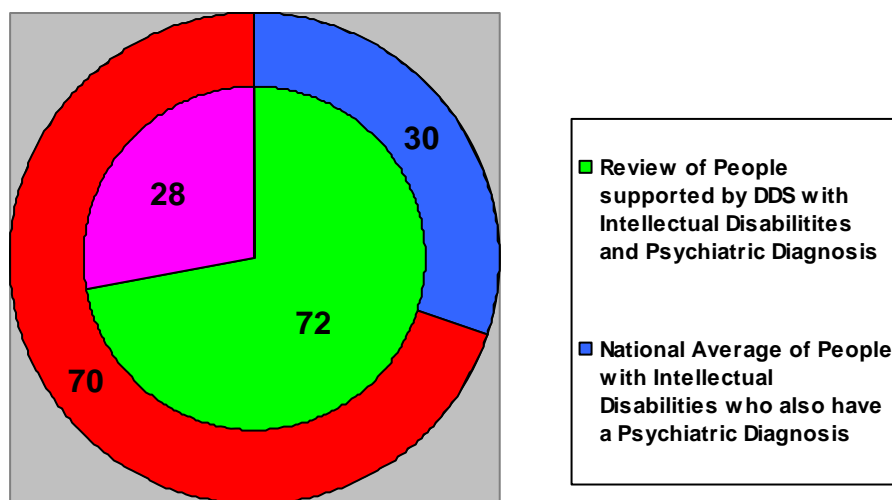
- 38% of BSP's contained no documentation of approval by DDA's RCRC

Dual Diagnosis

Dual Diagnosis is a term applied to people who have a diagnosis of co-existing intellectual or developmental disabilities and mental health issues.

- 164 of the 228 people (72%) 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 is a much higher rate than would normally be expected. As we've noted in previous reports, according to the National Association for the Dually Diagnosed, "30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder".²

Percentage of Individuals with dual diagnosis, National vs. Local



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). Many medications prescribed for diagnosed mental health conditions are of specific concern because of their potential for long term debilitating side effects. Through our participation in the Restrictive Controls Review Committee (RCRC) we became more aware of current DDS policy and provider practice regarding use of psychoactive medications in relation to implementation of Behavior Support Plans by providers, so we added several questions to our tool which will help us understand provider compliance with proper protocols governing the use of these medications.

- 135 people were taking more than one psychotropic, or neuroleptic medication

Of the 39 people monitored with additional questions added to our tool

- 47% did not have documentation of appropriate approval to use the medications

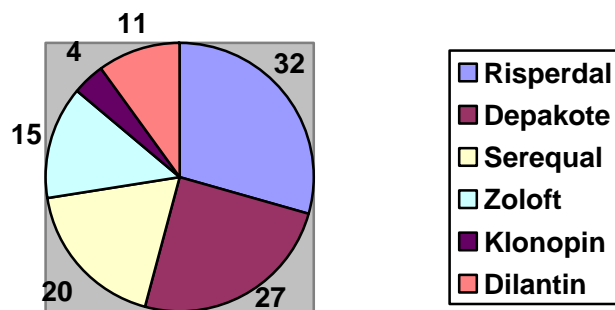
² "From the website of the National Association for the Dually Diagnosed, About NADD, Information on Dual Diagnosis"

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:

- 33 (16%) took Risperdal®
- 23 (11%) took Depakote®
- 15 (7%) took Serequel®
- 9 (4%) took Zoloft®
- 8 (4%) took Klonopin®
- 9 (4%) took Dilantin®

We also noted the following data:

- 3 people were taking psychotropic medications with no axis 1 diagnosis, in violation of DDS policy
- 2 people were taking psychotropic medications with no behavior support plan in place, a violation of DDS policy
- 16 people were prescribed three or more psychotropic medications



Medication Use

- 135 people (64%) were found to be taking multiple medications (these medications were a mix of neuroleptic and psychotropic medications).
- 27 (12%) people took only one neuroleptic or psychotropic medication
- 66 (29%) people took no psychotropic or neuroleptic medications

Conclusions:

We found again this year that the non Evans Class members we met do not present with the number of co occurring medical conditions or complexity as do many of the Class members. When Quality Trust staff do meet people for whom concerns are present it has been our policy to refer people to the District of Columbia Health Resources Partnership (DCHRP). We do nonetheless have concerns about the numbers of people, both Class and non Class members reflected in the SRI data in the categories of 911 Emergency, and Emergency Inpatient Hospitalization. There was a dramatic increase in these categories. We do not yet have a definitive explanation for this increase. It is 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. It is also possible these numbers reflect an inability of staff to manage known conditions such as an onset of seizure activity in a person with epilepsy. We will continue our tracking and trending analysis of this data in the coming year so we better understand the causes for these increases. We will also enhance our tool to further focus on the issues we have come to know are present in the people we meet.

A dual diagnosis was noted for almost three quarters of the non-class members we reviewed (72%, 164 people). As we noted last year, this is nearly double the national rate. In last year's report we recommended that steps be taken to reduce the use of psychotropic medications and our findings this year are that for the group of people we met use went down slightly from 74% to 71%. It is concerning however that use of multiple medications increased from 55% to 59% this year. This might reflect the fact that while fewer people are being prescribed psychotropic medications, more of those that are taking the medications are taking more than one. Of the people we met who are prescribed psychotropic medications; fully six in ten are prescribed multiple medications. This is of great concern. It was our believe last year that overuse of these medications masked a lack of more meaningful behavioral health supports. Our experiences this year have only amplified that view. From our SRI follow up we know that 911 Criminal is a category of incidents which many times involves a behavioral episode in which staff have been unable to deescalate the situation, and generally involves calls to the police, and escort to Comprehensive Psychiatric Emergency Program (CPEP). In fact 57 (88%) of the 65 Serious Reportable Incidents for 911 Criminal, and 22 out of 24, or (92%) for suicide attempt or threat involved non Evans Class members. Countless times in our follow up of these types of incidents we found the initial causes of the fracas which resulted in police being called were power struggles between staff and the people being supported. Some examples were, whether or not a person could smoke a cigarette, whether a person could choose to go to sleep at a time of their preference or not, whether a person could refuse to do chores, or bathe at the time requested by staff.

INCIDENTS AND INVESTIGATIONS

Quality Trust tracks the reporting of Serious Reportable Incidents (SRI's) for class and non class members. Data on the number and type of incidents reported is reviewed and reconciled monthly with staff from the Department on Disabilities Services (DDS); Developmental Disabilities Administration Incident Management Enforcement Unit (IMEU). This process ensures that the information received by Quality Trust matches what has been received by DDA. We also track the completion and timeliness of required investigations of incidents. Data is summarized quarterly and provided to DDS and the Court Monitor for review and feedback.

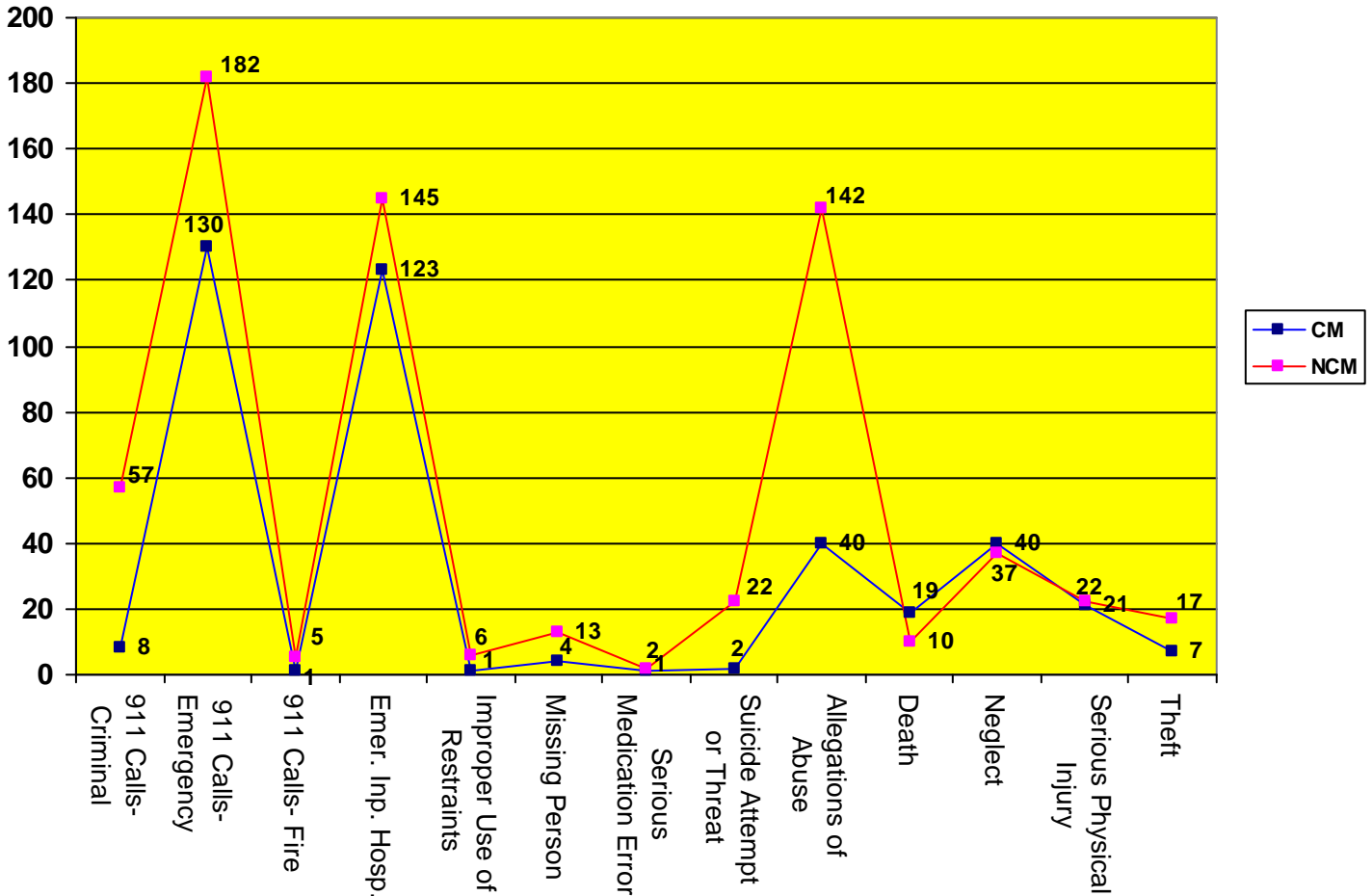
The process for tracking and reporting information on incidents and investigation used by Quality Trust was jointly developed with the administration based on shared understanding of expectations and policy. We have worked hard to keep an open and cooperative working relationship around this process. Over the past year, the IMEU has begun making changes in its internal protocols that impact this established process. For example, the person who was reconciling SRI's has been reassigned and DDS has decided not to refill that position According to the Supervisory Investigator, she will now take on the task of reconciliation. Additionally, we were recently informed that the category of "administratively closed", which reflected that the incident was closed without further investigation beyond what was completed by the provider, is not currently being used. Other changes in the current process are being proposed by DDS. Going forward, in the wake of these changes, we will request a meeting of senior staff from DDA, the Monitors from Quality Trust, and the Court Monitor to ensure that changes are understood, and accepted by all of those who use the Incident Management data.

The data reflected in this report is based on the processes previously agreed to by DDA and the IMEU.

Serious Reportable Incidents:

During the period of October 1, 2008 through September 30, 2009, 656 incidents were reported for non class members, which accounts for 62% of the total 1057 Serious Reportable Incidents reported for people receiving services in the District of Columbia. 401(38%) incidents were reported for Class Members.

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 from October 1, 2008 through September 30, 2009 (656 Serious Reportable Incidents)

Serious Reportable Incidents & full investigations

- 34% (18) of the NCM investigations received by QT, and due by September 30, 2009 were investigated within the 45 day compliance timeframe
- 66% (35) of the NCM investigations received by QT were not completed within the 45 day timeframe.
- There were 404 NCM investigations due, which have not yet been received by QT. 34% (138) of those due but not received are level 1 incidents, requiring a full investigation by IMEU policy
- 110 of the 138 on the NCM investigations involve allegations of abuse (87), and neglect (23)

Serious Reportable Incidents & Administrative Closure

- 52% (77) of the NCM investigations received by QT were administratively closed by IMEU, after review of provider internal investigations, but not closed within the 45 day timeframe
- 18% (17) of the NCM investigations received by QT that were closed administratively were closed within the 45 day timeframe, after review of provider internal investigations
- 1 of the NCM investigations that was administratively closed by IMEU was for a level 1 SRI. By IMEU policy, all Level 1 serious reportable incidents require full investigation, and should never be administratively closed
- Overall, out of the 551 investigations due for NCM (level 1 & level 2), only 27% (147) were received by September 30, 2009

The chart below contains a comparison of both level 1 and level 2 incidents in FY 2008 and 2009.

Comparative Analysis of Level 1 & 2 Incidents involving non class members, FY 2008-2009

INCIDENT TYPE	NCM		CM	
	FY 08	FY 09	FY 08	FY 09
<i>911 Calls- Criminal</i>	11	57	3	8
<i>911 Calls- Emergency</i>	58	182	44	130
<i>911 Calls- Fire</i>	3	5	0	1
<i>Emergency Inpatient Hospitalization</i>	87	144	105	124
<i>Improper Use of Restraints</i>	18	6	0	1
<i>Missing Person</i>	11	13	4	4
<i>Serious Medication Error</i>	1	2	1	1
<i>Suicide Attempt or Threat</i>	8	22	2	2
<i>Allegation of Abuse</i>	87	140	37	42
<i>Death</i>	15	10	15	19
<i>Neglect</i>	45	37	55	40
<i>Serious Physical Injury</i>	15	21	14	22
<i>Theft</i>	17	17	8	7

Comparison of Investigations Received involving Class and non Class members FY 2009

INCIDENT TYPE	NCM FY 09		CM FY 09	
	# 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>	57	38	8	3
<i>911 Calls- Emergency</i>	182	107	130	32
<i>911 Calls- Fire</i>	5	5	1	1
<i>Emergency Inpatient Hospitalization</i>	144	91	124	16
<i>Improper Use of Restraints</i>	6	5	1	0
<i>Missing Person</i>	13	8	4	1
<i>Serious Medication Error</i>	2	2	1	0
<i>Suicide Attempt or Threat</i>	22	10	2	0
<i>Allegation of Abuse</i>	140	87	42	8
<i>Death</i>	10	5	19	14
<i>Neglect</i>	37	23	40	8
<i>Serious Physical Injury</i>	21	9	22	8
<i>Theft</i>	17	14	7	3

Level 2 Incidents involving non Class members

- 911 Criminal incidents increased from 11 incidents to 57
- 911 Emergency increased from 58 incidents 182
- Emergency Inpatient hospitalization increased from 87 to 144
- Also increasing was Missing Persons, which increased from 11 incidents to 13
- Improper use of restraints decreased, however, from 18 incidents to 6

Level 1 Incidents involving non Class members

- Allegations of Abuse rose dramatically from 87 to 140
- Neglect allegations decreased from 41 to 37
- Serious physical injury increased from 15 to 21
- Theft stayed consistent at 17

Qualitative Review of Incident Investigations

Quality Trust monitors reviewed 103 Level 1 and Level 2 investigations 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.

Overall the investigations this year show improvement in certain key areas. We observed for the first time indications of tracking and trending of Serious Reportable Incidents as demonstrated by statements reflecting the fact that a potential perpetrator's criminal background check was accessed. Also several investigations reviewed, referenced connecting previous incidents which were documented in the database (MCIS). In several instances it was specifically noted that medication records, provider nursing notes, and staff progress notes were reviewed by IMEU investigators.

We continue to be concerned with the amount of investigations that are over the 45 day limit; in many instances several weeks to in some cases months overdue. There seemed to be a desk audit approach used to investigate 911 Emergency Medical, and Emergency Inpatient Hospitalization SRI's. We would like to have seen a more consistent approach to the disposition of these SRI's, because investigations differed in rigorousness, and thoroughness regarding follow up recommendations.

- 104 investigations were reviewed and analyzed
- 27 investigations were completed within the 45 day time frame (26%)
- 77 investigations were completed after the 45 day time frame (74%)

Conclusions:

There was a dramatic rise in the number of Serious Reportable Incidents (SRI's) filed this year. Last year there were a total of 664 SRI's, while this year there were 1057, an increase of 393. The biggest area of increase occurred in the categories of: 911 Emergency, and Emergency Inpatient Hospitalization. Last year there 102 SRI's in the 911 Emergency category, whereas this year there were 312, an increase of 210. Likewise, last year there were 192 SRI's in the category of Emergency Inpatient Hospitalization, and this year the number was 268, an increase of 76.

It is DDA policy that investigations of SRI's be completed in 45 business days. Quality Trust received 225 level 1 Serious Reportable Incidents involving non Evans Class members covering the period 10/1/08 through 9/30/09. All level 1 SRI's require a full investigation. As of September 30, 2009, 138 (61%) of those investigations were not received by Quality Trust. Within the 138 investigations not received are 87 for Allegations of Abuse, and 23 for neglect. The failure to produce investigations for these 110 incidents is unacceptable, and calls into question the ability of DDA to ensure the health, safety, and well being of non Evans Class members as relates to the completion of timely definitive investigations of potential exploitation and harm.

Our efforts to track and trend DDA's performance regarding compliance with the 45 day timeframe were complicated by the fact that DDA practice currently does not match policy. Our understanding of the current policy dictates that DDA can accept provider investigations (or "administratively close") certain level 2 SRI's at their discretion. It appears that beginning sometime between March and April of 2009, practice changed, as we no longer received investigations containing the wording "Administrative Closure". We were not officially notified of this change. It appears that IMEU staff began conducting full investigations of all level 1 and level 2 SRIs in the month of April. When the data is viewed through that lens, 404 investigations (73%) involving non Evans Class members were due but not yet received by September 30, 2009.

This is especially troubling because we found, and reported on this failure last year. Not only was no progress made on this issue, but by proportion fewer investigations were received by Quality Trust this year. We notified the Deputy Director of DDA of our concerns in July, and again in September, and it is our understanding that DDA is in the process of making changes to the current process for investigating Serious Reportable Incidents.

We strongly encourage DDA to develop, implement, and clearly define a new process which can quickly and thoroughly complete investigations of Serious Reportable Incidents for both Evans Class, and non Evans Class members.

FINAL COMMENTS AND SUMMARY

It is clear from our data and personal observations that changes continue to be made in efforts to improve the quality of supports and services for people with developmental disabilities in DC. Quality Trust has long advocated that the individual support planning process be the responsibility of the service coordinator. This change was implemented this year. While there was no immediate improvement in the quality of the plans reflected in our data, there was also no significant decline in the timeliness or quality of the plans. This means the change was made and managed without disrupting service delivery. Given the level of training, supervision and support required in making this change, this can be considered a significant accomplishment. This should set the stage for a more personalized and effective planning process going forward.

It is also encouraging that the DDA Deputy Director has been identified as the lead to coordinate efforts across District agencies that share responsibilities for ensuring people get access to needed supports. Specific agencies such as the DC Health Care Financing Administration and the Health Regulation and Licensing Administration have major responsibility and impact on what happens for people with developmental disabilities through their financing and enforcement authority. This process was only recently implemented and the administrator has already begun to use this process to address concerns about services. We hope that other areas (needed changes to waiver transportation, provider management and regulatory reform) will also be addressed quickly and effectively as everything related to these critical functions needs to be well coordinated in order for people to get the support they need, especially in times of limited fiscal resources.

It remains disappointing that the data does not reflect more progress in making practice more consistent with contemporary expectations and standards to promote individual autonomy and integration within the community. While the lack of progress is directly reflected in the specific data collected about the offering of personal choices and involvement in community activities, it is also reflected in some of the findings about behavioral healthcare and incident management. Our incident follow-up activities have revealed numerous incidents where staff demands for people to “follow the rules” or “comply” with schedules or activities have caused people to get angry and have “outbursts”, have escalated into physical altercations and ultimately resulted in 911 calls requiring a police response and/or trips to the hospital or mental health crisis unit. We have also been directly involved in other situations where individual preferences and opinions have been ignored or discounted in developing support plans. At best, this is a reflection of poor practice and creates unnecessary tension between the person and the people who are supposed to support them. We are led to question whether this is also leading to other more negative outcomes given the high number of 911 criminal incidents and the high incidence of prescription of diagnosis of co-occurring mental health concerns for non Evans Class members. We intend to study the available data in these areas more closely in the coming year.

Because of the observations and results reflected above, we strongly support the efforts of the DDA to establish a citywide, values based training initiative. Meaningful change in the areas of choice, respect and positive approaches to personal support will require ongoing investments in training and other actions to help people throughout the system to think differently about what can be expected from people who have developmental disabilities and the role of staff and other support personnel.

Finally, we do not understand the delay in completing investigations for non Evans Class members, especially for incidents of abuse and neglect. As of September 30, 2009, there were 110 investigations due, but not yet received by Quality Trust in just these two areas. We are also concerned about the lack of clarity around

protocols for tracking and trending serious reportable incidents and the follow-up investigation process. These are systems where we were working collaboratively with the administration in the past and where we see an important need for transparency and continued collaboration in the future.

The incident and investigation system is critical to understanding what is happening for people related to basic health and safety. Multiple trips to the emergency room, accidents at home that result in broken bones, significant injury or worse, and allegations of abuse or neglect can tell an instructive story about the day-to-day life experience for people with developmental disabilities. We do not expect to ever have a system that is free of accidents or other serious incidents – but we would expect that these kinds of occurrences would be reduced to a minimum through a process of review, investigation and changes in practice. That these “systems” at both the provider and government level are not yet strong enough to do this remains a serious concern.