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Through Partnership*

Quality Trust Monitoring Unit Report and Data Summary

Annual Report

October 1, 2007 – September 30, 2008

Introduction

Many initiatives have been undertaken in the last two years by government and service providers to reform the “system” of services and supports offered to people with developmental disabilities in the District of Columbia. Vast sums of money have been spent, great talent recruited, and real progress has been realized in certain areas. That said, little has changed in the day-to-day lives of many people supported, and this is especially true for those people not part of the Evans class action lawsuit. Quality Trust staff is confronted with this fact every day.

There are many ways in which Quality Trust touches the lives of people receiving services. The supports offered by QT are rooted in the notion that the only worthy system is one that begins with and does not compromise the belief that all people have capacity. With the right services and supports, they are able to decide how best to conduct their own affairs. People and their families want a system that treats them with respect and helps them create the kind of lives that anyone else desires. The role of all those in the system then should be to presume capacity, and promote, expand, and defend it. In this report we will show that too little emphasis is placed on presuming, promoting, expanding, and when necessary, defending capacity. We feel that this characteristic of the system of services and supports in the District of Columbia is a major cause for little real change in the daily lives of people with developmental disabilities.

Monitoring was a critical function identified for Quality Trust in the 2001 Settlement Agreement and Plan for Compliance and Conclusion of Evans v. Williams. QT’s charge was to “monitor modifiable risk factors” for non Evans class members with developmental disabilities as well as prepare to assume responsibility for independent, external monitoring for all people receiving services at the conclusion of the lawsuit. Over the past three years QT has developed processes, tools and staff capacity for ongoing monitoring to address our charge in this area.

Methodology

The first monitoring tool used by Quality Trust was developed with support from The Council on Quality and Leadership (CQL) using their Basic Assurances tool as a reference. CQL (formerly know as The Accreditation Council on Services for People with Developmental Disabilities) is an independent, nonprofit organization with expertise and experience in setting standards for services and supports to people with disabilities. CQL staff has certified all QT Monitors in Personal Outcome Measures and two Monitors as Certified Quality Analysts. CQL worked with QT Monitoring staff to establish a person centered approach to monitoring. There were two main components to the tool and process developed:

1. An individual review to look at service quality from each person’s experience
2. A systemic review to look at whether the provider organization had developed and implemented policies and procedures in critical areas throughout all operations.

CQL provided training for QT monitoring staff. The tool and process were tested during a trial period with opportunity for feedback from the provider community. The process included interviewing a sample of non-class members with high numbers of serious reportable incidents and an additional 10% random sample of other non class members receiving residential support from the provider organization being reviewed. Response to the process was generally favorable with some concern expressed about the overall expectations for performance being too new and or difficult for many providers.

Based on field experience and feedback from providers, the monitoring tool was reformulated to address basic performance expectations found in local DDA policies and procedures, requirements of the 2001 Plan for Compliance and Completion and the human care agreement in FY 2006. Providers, Evans Monitors, people with disabilities and the Department on Disability Services (DDS – formerly the Mental Retardation and Developmental Disabilities Administration) participated with QT in refining the monitoring tool and ensuring critical data elements were included. The use of the systemic review was suspended in the spring of 2007 when DDS began implementation of their Basic Assurance Standards Authorization (BASA) process. We chose to suspend the process because QT's systemic review included items similar to the BASA process and we did not want to risk causing confusion among providers as DDS implemented its new quality review process. The individual assessment and interview format were retained and implementation continued.

QT's Monitoring Unit also has responsibility for ensuring that all Serious Reportable Incidents reported to DDS are reviewed and follow-up occurs as needed. QT regularly receives copies of the reports filed with DDA by provider agencies. The QT Monitoring Coordinator reviews all individual reports and makes determinations about needed follow-up. Copies of reports are forwarded to QT Advocates if they are actively involved with the named person. In situations where there is an immediate concern about the person's welfare or facts surrounding an incident are not clear, a QT Monitor is assigned to do individual follow-up. Data is entered into a database to allow for trending and tracking of data. Reports are created and updated on a semi annual schedule to identify issues.

This report reflects data collected during the Fiscal Year covering October 1, 2007 through September 30, 2008. It includes data for 212 non Evans class members receiving services in the District of Columbia. Information was collected by QT Monitors from Serious Reportable Incident reports; review of files, and from individual monitoring reviews.

The report is organized into the following four areas:

1. Demographics
2. Health Care
3. Individual Support Plans
4. Incidents and Investigations

Demographic Information

The activities of the Monitoring Unit at Quality Trust focus on reviewing the quality of services and supports to those people that are not members of the Evans Class. According to DDS in June 2008, there are a total of 1,384 non class members. The following chart reflects the age breakdowns of those 1,384 people.

Non-Class Members receiving DDA services by age group

Age	Number	Percentage
21 - 30	501	36%
31 – 40	341	25%
41-50	321	23%
51-60	132	9%
61-70	62	4%
71-80	23	2%
81-90	4	>1%
Total	1,384	

This data confirms that 85% of non class members are 50 years of age or younger. It is our understanding that the youngest Evans class member is 38 years old. Approximately 89% of class members are age 51 and older.

Non Class Members Reviewed by Quality Trust

The data presented below are broken down relative to age, type of residence, and source of funding. This report includes only non class members living outside of their family home. We attempted to define the exact number of non class members living outside the family home, but DDA was unable to give us that information. The information in this report was gathered through record review in the person's home and from information contained in the DDS database known as MCIS.

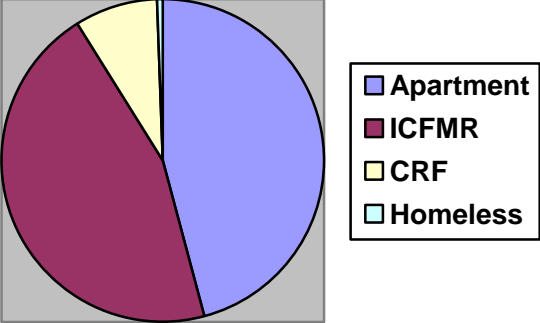
Age

- The highest percentage of people (29%) or 62 people are between the ages of 31 and 40.
- 57 people (28%) are between the ages of 20 and 30.
- 56 people (26%) are between the ages of 41 and 50.
- 37 people (17%) are age 51 and over.

Type of Residence

- 97 people (46%) live in apartments.
- 96 people (45%) live in a home certified as an Intermediate Care Facility for People with Mental Retardation (ICF/MR)
- 18 people (8%) live in Community Residential Facilities (CRF)
- One (1) person is homeless.

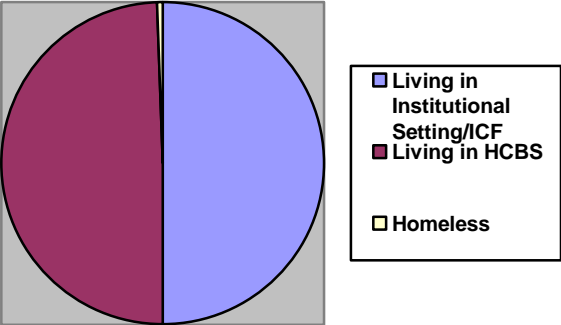
Graph 1 Types of Residence



Funding Source

- 96 people (45%) live in institutional placements (ICF/MR)
- 115 people (54%) live in placements funded through the HCBS waiver
- 1 person is homeless

Graph 2 Funding Source



Review of Health Care

Potential Health Risk Assessment:

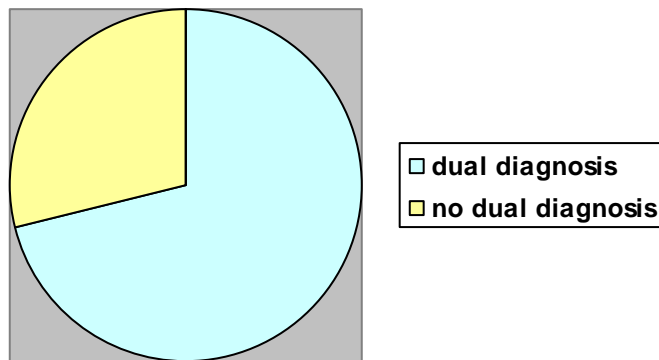
Quality Trust uses a standardized checklist to identify people with conditions that can increase their risk of health problems. A point value is assigned for the presence of specific health concerns and significant changes in behavior (see addendum). The Quality Trust Consultant Nurse visits people with a score greater than 100 points, conducts a review of their health status and care, and prepares a report which is then shared with the individual and the people who support that person.

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.

- 151 of the 212 people (71%) had co-occurring Axis I and Axis II diagnoses (dual diagnoses) indicating the presence of a mental health condition in addition to an intellectual disability. This is a significant finding because of its clear implications on the lives of the people affected, as well as for fiscal and program policy going forward.

Graph3 Individuals with dual diagnosis



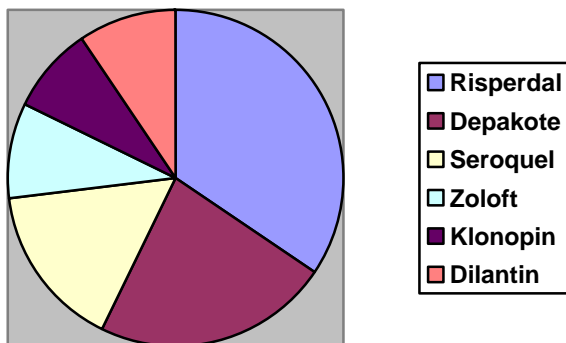
Medication Use

Psychotropic medications:

The QT collected and reviewed detailed data regarding prescribed psychotropic and seizure medications. We specifically emphasized the identification of people taking more than one medication at a time for a single condition (polypharmacy). Medications prescribed for mental health disease are of specific concern because of their potential for long term debilitating side effects. We found that 116 people (55%) were taking more than one psychotropic, or neuroleptic medication. The most common medications were:

- Risperdal, taken by 33 people (16%)
- Depakote, taken by 23 people (11%)
- Seroquel, taken by 15 people (7%)
- Zoloft, taken by 9 people (4%)
- Klonopin, taken by 8 people (4%)
- Dilantin, taken by 9 people (4%)
- 3 people were taking psychotropic medications with no Axis 1 diagnosis
- 2 people were taking psychotropic medications with no behavior support plan in place
- 16 people were prescribed three or more psychotropic medications

Graph 4 Medication Use



- 135 people (64%) take a combination of seizure and psychotropic medications
- 22 (10%) people take only one seizure or psychotropic medication
- 55 (12%) people take no psychotropic or seizure medications

Health Risk Management Plans:

DDS has stated that their goal is to establish Health Risk Management Plans for all people supported. Therefore, as part of the QT health data collection protocol, QT advocates and monitors review medical records and collect data to determine whether a person has a Health Risk Management Plan in place. We found that :

- 200 people (94%) had a Health Risk Management Plan.

DDS has done a good job of developing Health Risk Management Plans for the non class members we reviewed. In our next monitoring reviews we will look at the Health Risk Management Plans and concentrate more specifically on the effectiveness of case management by provider agency nurses and DDS service coordinators.

Personal Interview:

The following information relating to choice and autonomy of personal healthcare is derived from personal interviews of those reviewed:

- 17 people (8%) reported choosing their own doctor.
- 10 people (5%) reported choosing their own dentist.
- 127 people (60%) reported that they receive healthcare at locations where those without disabilities receive healthcare.

These data reflect a significant lack of choice and personal autonomy in decision-making by those receiving supports. When one considers the personal nature of the relationship with one's doctor or psychologist, it is disturbing that only 8% and 5% of people respectively were able to make that decision on their own behalf. On the other hand, it is a positive development that 60% of those interviewed state that they receive their services in a setting that also serves people without disabilities.

Conclusions:

We noted a dual diagnosis for 71% of the non-class members we reviewed. This is greater than double the national rate. According to the National Association for the Dually Diagnosed, "30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder".¹ Additional analysis of this finding is necessary in order to plan for the needs of this group going forward. The current reliance on psychotropic medications as a strategy to decrease unwanted "behavioral problems" (55%) may be masking the absence of good, sound, communication- based positive behavioral supports as a practical alternative. Not all people with a dual diagnosis are taking psychotropic medications, but the numbers are concerning, and reductions whenever and wherever possible should be sought. On the whole, non class members enjoy relatively good health. Diminishing the use of psychotropic and seizure medications could offer increased opportunities for people to exert greater control over personal lifestyle and healthcare decisions. Better practice in this area might also generate substantial savings in the amount of money currently spent for 1:1 personal supports.

It should be of great concern that relatively few of the people we interviewed are able to choose their own doctor or dentist. In our opinion this is a sign of a fundamental shortcoming of the nature of service provision in the District of Columbia.

¹ "From the website of the National Association for the Dually Diagnosed, About NADD, Information on Dual Diagnosis www.nadd.org 11.20.08"

Individual Support Plans

Current ISP:

- 168 people (79%) had a current DDS-approved Individual Support Plan.

Community Connections:

The real work of supporting people with developmental disabilities to have better, more meaningful lives is to offer them safe and healthy opportunities to gain experience managing their own affairs. An ISP should contain strategies to create and expand community experiences, and/or relationships. The ISPs we reviewed lack quality relative to creating strategies to identify and expand opportunities that would enable people to develop for themselves the kind of lives they desire. Community connections refer to those parts of the ISP that discuss the person's community integration preferences and strategies for success. Becoming more integrated into one's community should be the very foundation of services and supports funded through the HCBS waiver. With that in mind we offer the following observations:

- 92 people (43%) had barriers identified in their ISP that may limit their ability to make meaningful connections in their community. Barriers may include, but are not limited to, behavioral issues, lack of staff, and lack of transportation.
- 17 people (8%) had a community strategy plan and goals in their ISP designed to establish or expand community relationships. A strategy may be a daily visit to the local coffee shop or a partnership with the community book club in order to build relationships. These strategies should be rooted in the person's strengths and interests.
- 89 people (42%) had an ISP that described the necessary staff support for community integration activities.
- 55 people (26%) had QMRPs or House Managers trained to assist the person in establishing goals and outcomes targeted toward community integration.

Choices and Preferences:

- 42 people (20%) had their preferences stated in their ISP in regard to their community integration.
- 33 people (16%) had one type or another of inventory or checklist in their ISP describing how the person would be supported regarding creation or expansion of community integration activities.
- The ISPs of 9 people (4%) had an evaluation of the effectiveness of community integration activities and their outcomes.

Behavior Support Plans

DDS policy states that people taking psychotropic medications have a Behavior Support Plan. Quality Trust collected data for those with a recommended Behavior Support Plan.

- 140 people (66%) have a recommended Behavior Support Plan.

Personal Interview

During the monitoring process everyone receives the opportunity to tell his or her story through a personal interview. We format questions as “yes” or “no”, with follow up questions designed to establish with the greatest possible certainty that both the question and the answer are clearly understood. We strive to ask questions in a manner that allows people with limited verbal communication to answer. At times a person refuses to talk or is unable to communicate in a manner that the monitor can understand. In that case, the person’s staff is asked the same questions. Most people are able to answer questions themselves. Here are some of the responses we obtained during our interviews:

- 18 people (8%) participate in a group or organization.
- 112 people (53%) participate in their own grocery shopping.
- 82 people (39%) report that they have friends without disabilities.
- 122 people (56%) state that they have met their neighbors.
- 136 people (64%) report having their own bedroom
- 147 people (69%) report participating in buying their own clothing.
- 101 people (48%) report that they open the door when the doorbell rings at their home.
- 72 people (34%) report that they use public transportation.

Conclusions:

An ISP is the fundamental building block of planning for people with disabilities; therefore, DDS Service Coordinators must ensure that current and approved ISPs are available in the homes of people who receive supports. During our visits, 79% of the people we met had a current ISP available for review.

It is not enough, however, to ensure that a current ISP is present. The plan must also serve as an opportunity for people to lead the support team in creating services and supports that reflect their true wants and needs. That only 26% ISP’s referenced a QMRP or House Manager trained to assist people to establish their own goals and outcomes indicates a deficiency on the part of providers to offer meaningful services and supports. This is an opportunity to recognize and expand capacity that has been lost to the detriment of the person.

The findings related to community integration contain both positive and negative elements, but overall tell us that there is limited support for the people we met to become connected within their community. Some relatively positive signs are present. For example, more than half of those interviewed said they have their own bedroom, and 69% said they participate in buying their own clothing. On the other hand, only 8% participate in a group or organization not affiliated with their provider organization, and only 34% report using public transportation. Only 53% of those interviewed participate in shopping for their groceries, and only 56% have met their neighbors. These are activities that are at the heart of community living. While many people are known to have barriers that inhibit their ability to enjoy greater membership in their community (43%), only 8% had ISPs containing strategies or goals to help them overcome these barriers. People with disabilities are not being empowered to gain the experience they need to become members of their communities and control their lives.

Incidents and Investigation

Quality Trust tracks the reporting of serious reportable incidents (SRIs) for class and non class members. On a monthly basis, we review and reconcile these incidents with staff from the Department on Disabilities Services (DDS); Developmental Disabilities Administration Incident Management Enforcement Unit (IMEU). This process ensures that the information Quality Trust receives matches what DDA receives.

According to their policy, the IMEU must complete a full investigation report within 45 business days of receipt of all Level 1 SRIs. Certain Level 2 SRIs may require a full investigation or can be administratively closed after review of the facts contained in the provider's internal investigation according to the judgment of the staff of IMEU. According to the Incident Management System policy created in 2006, administrative closures (review of provider incident investigations By DDA, IMEU staff) should occur in five business days from receipt. There were 82 investigations due by September 30, 2008 that QT had not yet received.

This incident report summary covers the timeframe from October 1, 2007 through September 30, 2008. This section of the report addresses incidents and investigations for everyone, not only those monitored during the timeframe of the report.

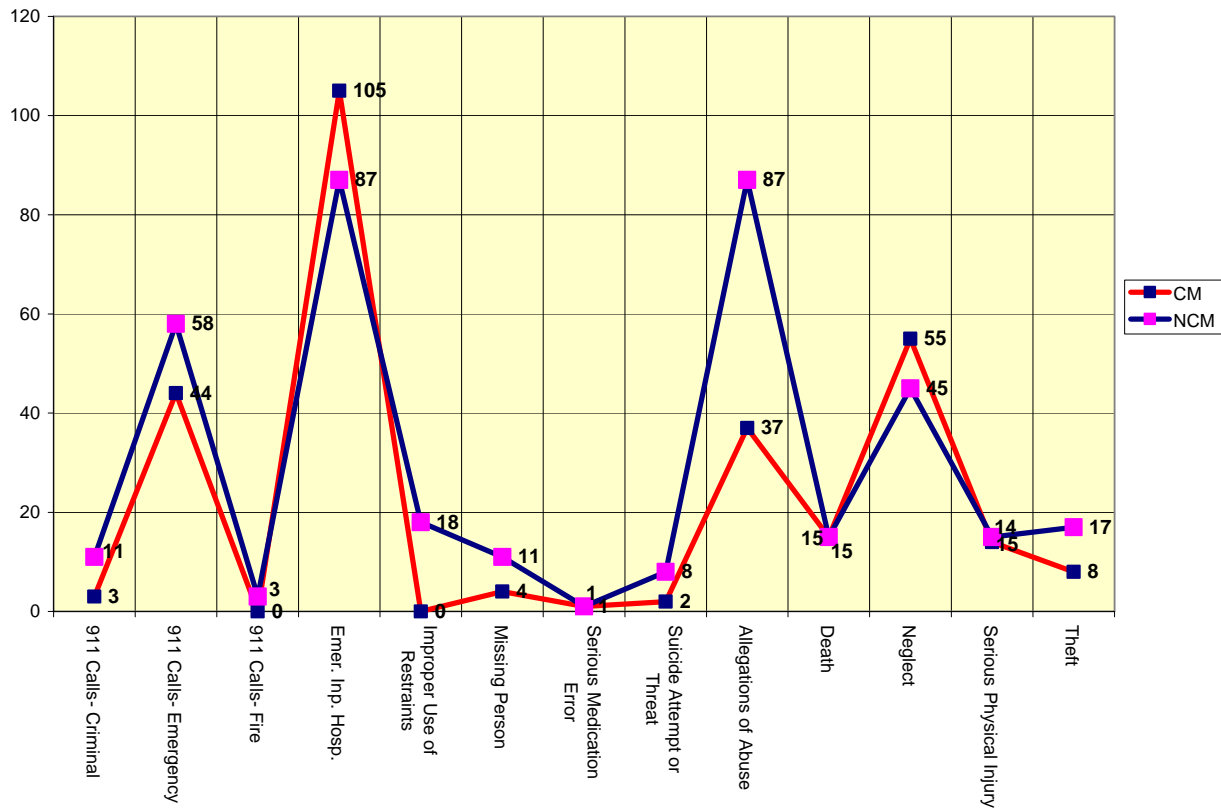
Analysis of Incidents involving Class Members and Non Class members

The graph below illustrates a class member vs. non class member comparison of fiscal year 2008 incident totals, by incident type. Notice that non class member involvement in incidents is higher in every category except emergency inpatient hospitalization and neglect.

- Non class members have significantly higher rates of criminal 911 calls, suicide threat, and missing person incidents.
- Non class members had 8 incidents (80%) of suicide threat/attempt reported, compared to 2 incidents (20%) for class members.
- Non class members had 11 (73%) missing person incidents reported compared to 4 (27%) incidents for class members.
- Out of 14 reported 911 criminal calls, non class members had 11 incidents (79%) compared to 3 (21%) incidents for class members.

These findings are not surprising given the high rate of dual diagnosis (71%) among non class members. Additional study is necessary, however, to understand the true nature of these patterns. These increased incidences could be related to the prevalence of dual diagnoses, or as stated previously, lack of adequate and appropriate services and supports. Given the profile of many non class members, the need for better mental health supports and behavior management strategies is clear.

Graph 5 Incident Breakdowns between Class and Non Class Members



Serious Reportable Incidents:

During the period between October 1, 2007 through September 30, 2008, 376 incidents were reported for non class members, which accounts for 57% of the total 664 SRIs reported for people receiving services in the District of Columbia. 288 incidents (43%) were reported for Class Members.

Investigation of Serious Reportable Incidents:

Quality Trust tracks investigations for all SRIs, the time frame 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, 2007 through September 30, 2008.

Serious Reportable Incidents & Full Investigations

- 41 (34%) of the NCM investigations received by QT, and due by September 30, 2008, were investigated within the 45 day compliance time frame.
- 81 (66%) of the NCM investigations received by QT, and due by September 20, 2008, were not completed within the 45 day time frame.

- There were 82 NCM investigations due, which had not yet been received by QT as of September 30, 2008.²

During the second half of the fiscal year there was improvement regarding timely closure of investigations. At the end of the second quarter 4% of investigations were closed within 45 days. As noted above that number increased to 34% in the last half of the year. A serious concern, which we must address as soon as possible, is the completion of only 34% of investigations within the 45 day time frame. .

Serious Reportable Incidents & Administrative Closure

- 79 (71%) 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 time frame.
- 33 (29%) of the NCM investigations received by QT that were closed administratively were closed within the 45 day time frame after review of provider internal investigations.
- Three of the NCM investigations that were administratively closed by IMEU were for incidents of Level 1 status. By IMEU policy, all Level 1 SRIs require full investigation and should never be administratively closed.

The effectiveness of the Incident Management System is reduced given the number of overdue investigations.

Comparative Analysis of Level 1 & 2 Serious Reportable Incidents involving non Class members

Chart 6 below contains a comparison of Level 1 and Level 2 incidents in FY 2007 and 2008. The reduction in the use of the 911 system should be noted as it may be an indication that direct support professionals are improving their responses to unplanned events. Allegations of abuse and neglect were reported at a significantly higher rate in FY 2008 than in any of the previous three years (see chart 7). This may be an indication of increased awareness of the need to report such incidents.

Chart 6 Comparative Analyses of Level 1 & 2 Incidents, FY 2007-2008

INCIDENT TYPE	NCM		CM	
	FY07	FY08	FY07	FY08
911 Calls- Criminal	41	11	6	3
911 Calls- Emergency	91	58	101	44
911 Calls- fire	2	3	0	0
Emer. Inp. Hosp.	93	87	109	105
Improper Use of Restraints	2	18	1	0
Missing Person	6	11	3	4
Serious Medication Error	5	1	1	1
Suicide Attempt or Threat	5	8	1	2
Allegations of Abuse	58	87	44	37
Death	12	15	17	15
Neglect	37	45	28	55
Serious Physical Injury	27	15	26	14
Theft	6	17	8	8

² From October 1, 2008 until November 14, 2008 QT received 54 of the 82 investigations. They are not included in this report, but we will review them and include them in our next report

Level 2 Incidents involving non class members

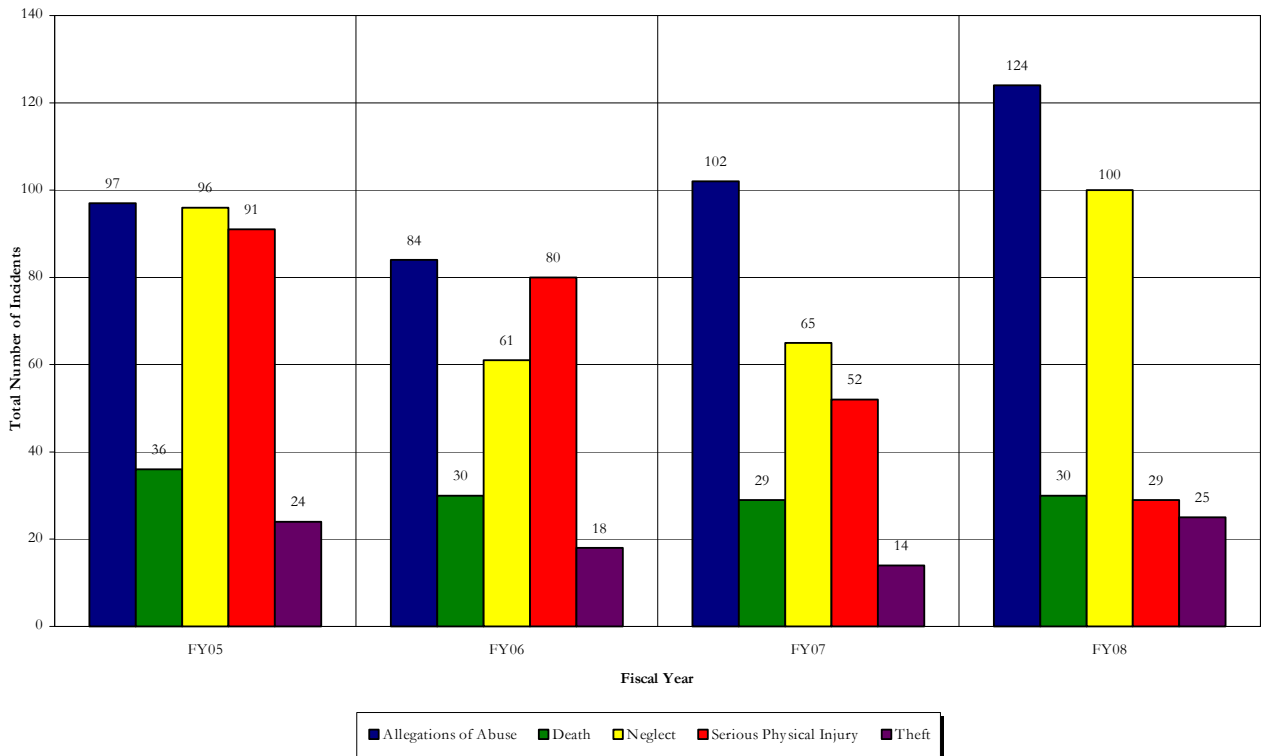
- 911 criminal incidents decreased from 41 incidents to 11
- 911 emergency incidents decreased from 91 incidents to 58
- emergency inpatient hospitalization decreased from 93 to 87
- improper use of restraints rose dramatically, however from 2 incidents to 18
- missing persons incidents increased from 6 incidents to 11

Level 1 Incidents involving non class members

- allegations of abuse rose dramatically from 58 to 87
- neglect allegations rose modestly from 37 to 45
- serious physical injury decreased from 27 to 15
- theft rose from 6 to 17

Level 1 and 2 SRIs are among the most serious incidents in which a person might become involved. The chart below displays a comparative analysis of Level 1 incident totals from FY 2005 to present

**Chart 7 Comparative Analysis of Level I Incidents, Fiscal Years 2005-2008
(Includes incidents for Class members & non Class members)**



Qualitative Review of Incident Investigations

Quality Trust monitors reviewed 80 Level 1 investigations (defined as allegations of abuse, death, neglect, serious physical injury, and theft) using the “Checklist for Reviewing Investigation Reports for Comprehensiveness and Quality,” tool (See attached). This tool is designed to track collected data and the time frames required to complete investigations, documents reviewed by investigators during their investigations, interviews conducted of witnesses, victims, and people involved, any other evidence gathered. All Quality Trust monitors have successfully completed the DDS investigation training and passed the exam.

- 80 investigations were reviewed
- 10 investigations were not dated
- 14 investigations were completed within the 45 day time frame (20%)
- 56 investigations were completed after the 45 day time frame (80%)
- Several investigations contained conflicting and confusing statements
- Several investigations contained boiler plate capacity statements presumably taken from ISPs
- Very few investigations contained recommendations that would reduce the possibility of harm in the future
- One Level I incident investigation was administratively closed, contrary to DDS policy

Conclusion:

While there was an overall decrease in SRIs from last year to this, abuse, neglect and improper use of restraints were reported at a significantly higher rate. There was a significant reduction in the use of the 911 system involving non class members. Only 34% of investigations involving non class members were completed within the time frame established by DDS policy, a rate that must be addressed with utmost urgency. It is equally disturbing that 71% of incidents were closed administratively by DDS after review of provider investigations but not within the 45 day time frame. This seems illogical in that, if the facts do not warrant further investigation, the only reasonable next step is to take those actions that would allow for closure of the record. The most concerning finding, however, is that 28 investigations due by September 30, 2008, are incomplete and will carry over and be added to the 21 investigations from FY 07 still outstanding, and not received by QT as of the distribution of this report. It is vitally important for the protection of the people receiving supports that the DDS Incident Management System can quickly investigate incidents and resolve potential dangerous situations.

Overall, non class members are younger than class members. For people living out of the family home, the majority in this report were either living in apartments with no more than one roommate or in group homes funded through the HCBS waiver (54%), although (45%) live in ICF's/MR.

- 1. DDS has set a goal of retaining approximately 125 ICF/MR beds (a decrease from more than 535 available now) through the Money Follows the Person demonstration grant. Quality Trust endorses this shift away from institutional services. Given the magnitude of change in practice required to meet this goal, however that number may prove unrealistic. What is of primary importance is that practice is truly changed in this effort. What must remain is capacity for providing high quality nursing and medical case management services for people with complex needs. DDS and MAA should continue to develop a new funding methodology for ICFs/MR, as this is a necessary step in that process. During this process of rebalancing, great care must be given to developing a higher quality provider base within the ICF/MR program. Particular attention must be paid to developing the capacity of Direct Support Professionals in those organizations until they are highly trained, highly paid, and highly appreciated for the work they do.*
- 2. The addition of funding accessed through the Money Follows the Person grant should assist DDS to facilitate rebalancing into the HCBS waiver. Residential options such as In Home Supports, Host Home, and Live-in Companion are good alternatives for people who have never lived in institutional settings, and might also offer opportunities to reduce individual placement costs within the HCBS waiver.*

Approximately three quarters of the people we interviewed had a co-occurring diagnosis of intellectual disability and mental health concerns. This is higher than national statistics would predict. At this time and with the available data, we are not able to identify a specific cause for this finding. We strongly believe that additional analysis is warranted; therefore, we will continue to collect information around this issue in the future.

We offer these recommendations relative to provision of supports to people with a co-occurring diagnosis.

- 1. Experienced providers are desperately needed, particularly those experienced in supporting people with complex co-existing intellectual disabilities and mental health diagnoses and those within the autism spectrum. We understand that DDA is actively recruiting new providers to come to the District of Columbia, and we strongly support continuation and expansion of these efforts.*
- 2. Positive behavior supports should replace the use of psychotropic medications whenever and wherever possible. This is a model rooted in the belief that all behavior is a form of communication and therefore must be treated as meaningful. Through better understanding of how to communicate with people served, there may be instances where medications can be reduced or eliminated.*
- 3. In order to reduce the need for placements at St. Elizabeth's Hospital or other inpatient psychiatric settings, DDS must create short-term crisis services. DDS efforts to partner with the Department of Mental Health should continue and expand where warranted.*
- 4. Direct Support Professionals need more extensive training and support for assisting with medical consults and emergency room visits to ensure people receive appropriate supports and services. Residential providers must also ensure that staff members*

sent to support people at medical appointments have current, accurate information about the nature of the service required during the particular visit.

- 5. We need a greater number of psychologists and psychiatrists who have interest and expertise in supporting people with developmental disabilities. Efforts by the Health Care Resources Partnership at Georgetown University and DDS to locate and recruit qualified providers must continue. We also believe that the integration of information about supporting people with developmental disabilities into residency programs at area hospitals is a good strategy for the long term.*
- 6. We believe that the practice of prescribing three or more psychotropic medications should cease. Quality Trust will continue to track this practice and work with DDS to identify ways to reduce reliance on drugs as a treatment strategy over time.*

Just over three quarters of the non class members reviewed had current ISPs in their files at their residence The ISP is essential for good services and supports; and because it is so important, the process of timely completion must be seen by providers and DDS Service Coordinators as the most important opportunity to plan with the person. When questions arise about what a person wants and needs, serious and deliberate actions must occur to ensure that the person's preferences and future desires are understood. This creates the foundation for assuring basic health and safety, as well as helping people achieve important personal goals.

- 1. Fundamental changes are needed to improve the day-to-day lives of people with developmental disabilities. For example, service coordinators must become proficient in developing ISPs and ensuring that plans are implemented as written. We support the just implemented transition of ISP development from contractors to DDA Service Coordinators. This process began in October of 2008. This change will lead to greater emphasis being placed on seeing the person as the leader of the ISP development. Although DDS has begun this process, it may take one to two years to acquire the expertise needed to ensure that the plans reflect what is most important to and for the person receiving supports. Until the process works well for everyone in DC, this must be seen as a top priority.*
- 2. It is essential that the provider community elevate the quality of the services and supports they provide to people with developmental disabilities. Intensive and ongoing values-based training for direct support professionals, as well as increased regular supervision, is a responsibility of provider agencies.*
- 3. On October 15, 2008, Quality Trust, along with several providers, sponsored the 2nd Annual Direct Support Professionals Conference. The purpose of the conference was to offer enhanced training opportunities to those people upon whom we all depend for the supports that ultimately determine whether people's lives are safe, healthy, and meaningful. We distributed a survey the following two questions, "What resources or supports do you need to do your job better?", and "Do you plan to make this work a life long career? If not, what would it take for you to stay in this field and support people with developmental disabilities". Overall 57 people responded to the survey, and of those 40 responded to one or both of these questions. More than half of the responses (23) indicated that training was what was most wanted and needed. Direct Support Professionals are looking for training, and it is the responsibility of the provider community to provide it.*

Many SRI investigations (66%) were not completed in the 45 day time frame set in policy. 71% of investigations administratively closed were not closed in the required time frame.

Of the 82 reports not received by Quality Trust by September 30, 2008, 26 involve Level 1 incidents which require full investigations. 70% of the reports not yet received are from the first three quarters of the fiscal year. This is a serious failure which must be immediately addressed.

- 1. A protocol for ensuring that Serious Reportable Incident investigations are not only completed in a timely manner, but are also of the highest quality must be implemented as soon as possible. As stated earlier in this report, the system is compromised when a significant number of reports are late, and contain inaccuracies and contradictions. The recommendations made in these reports represent an inability of DDA to provide technical assistance and, if necessary, sanctions to poor or under-performing providers. The protocol must also include capacity to analyze tracking and trending of data gathered.*

Final Thoughts

This report provides a window into the lives of the 1,384 people who are not a part of the Evans litigation. We used record reviews and personal interviews of 212 non class members supported by 35 different residential providers. We used incident management data to identify trends and pressing issues. These people and those that will enter the system each and every year are the future of services and supports in the District of Columbia.

We know that as a whole, non class members are younger, physically healthier, and more apt to live at home with their families than members of the Evans class. We also know that within our review, a far larger proportion than would be expected carry co-existing diagnoses for which they are frequently prescribed psychotropic medications. We must improve the practice of supporting this group of people. Doing so will prevent the compromise of their physical health, and eliminate adding to their psychiatric and or psychological challenges. Without such improvements individual costs of services may remain unusually high when compared to most other states.

In most states a move from a large state institution to a waiver-funded alternative involves significant changes to many aspects of a person's day-to-day life. In the District of Columbia transitions from services funded through the ICF/MR program to waiver-funded options involve as little as moving around the corner or to a home a few streets away. From our monitoring and interviews it appears that often the only perceptible change is one's address. Too many people are missing opportunities to become more fully involved in the communities in which they live. Regular, meaningful, and varied training opportunities for Direct Support Professionals and others is needed to familiarize them with the importance of seeing their role as one of offering people endless avenues to become real members of their communities.

Many improvements have been made in the structure of the system. The Department on Disability Services was created in January 2007. Many highly competent DD professionals have come to DC to help transform the system into a viable model for the 21st century. A new and improved HCBS Waiver was developed and implemented in November 2007. This waiver will ultimately make it possible for people to take advantage of more unique and individualized services and supports. DDS has improved its ability to create policy based on experience, as well as revising policy and practice as needed.

These are all hopeful developments. People's lives do not improve solely because of improved policies and structure. People's lives get better because they get what they need when they

need it. In that way people with disabilities are no different than anyone else. We must improve the quality of the services provided and become more focused on developing that which is innate in every person served. We must improve case management services so that any person entering the system can be assured that their Service Coordinator is competent to develop an ISP which reflects their true needs and desires. Once that ISP is developed, the Service Coordinator must operate as the arbiter on behalf of the person to ensure that all necessary services and supports are provided. Finally, the Incident Management System overseen by DDA must improve significantly so that it can quickly determine when abuse, neglect, or other potential dangers are present. Once that determination is made, the process must follow through with intervention strategies that enhance the health, safety, and rights of all people supported. Tracking and trending of this data are essential if the District of Columbia is to truly create a continuous quality assurance and improvement capability.

Overall, the practice of supporting people with developmental disabilities in DC remains rooted in practices that do not recognize, acknowledge, or support their potential. When people are consulted about what is most important to them, they are frequently told that what they want is not possible or is contraindicated based on “professional “judgment. These practices will never produce quality in supports and services. Changes in policy and practice based on individual planning and rooted in positive values are key elements necessary to improve the day to day lives of people with developmental disabilities in the District of Columbia.