Quality Trust
for Individuals with Disabilities

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INTRODUCTION

January 10, 2017 was no ordinary day. In her opinion dated December 13, 2016, Judge Ellen Huvelle found that the District of Columbia had achieved compliance in the forty-year-old litigation brought on behalf of people who resided at Forest Haven, The District's lone institution for people with intellectual and other developmental disabilities. On January 6, 2017, the parties to the case jointly filed a motion requesting that the court vacate all outstanding court orders in the case. And then, at a hearing on January 10th, attended by former residents of Forest Haven, attorney's, advocates, providers and the current and former Mayor, Judge Huvelle signed the order ending *Evans* v Bowser.

The first resident of Forest Haven was committed on March 11, 1925. In the ninety-two years between that day and today a revolution has occurred in the way people with developmental disabilities live, and the method states use to organize and pay for the services they need. In 1925 there was no federal government involvement in the organization or funding for services for people with developmental disabilities, while today Medicaid is the primary source of financing people depend on to fashion lives of meaning in community based settings. As an example, per his final report in the Evans case, Special Master Clarence Sundrum noted that since 2000 the District of Columbia has obtained approximately 2.3 billion dollars of Medicaid funding with 1.6 billion coming from the Medicaid waiver. The waiver is known as the "home and community-based services waiver" (HCBS) because it allows states to support certain Medicaid populations in home or other community based settings rather than in institutional or long-term care facilities such as hospitals, nursing homes or institutions for people with developmental disabilities.

The 2001 Plan for Compliance and Conclusion in the *Evans* case included among its many outcomes the creation and funding of Quality Trust. Quality Trust was intended to be a permanent monitor and mechanism for safeguarding all people with intellectual and other developmental disabilities served by the District and to continue its operations after the termination of this action. Now that the case has been concluded Quality Trust is poised to fulfill our mandate to monitor and advocate for everyone receiving services through the auspices of the District of Columbia, Department of Disabilities Services.

What follows is the first of what will be four quarterly reports in Fiscal Year 2017, containing results from Quality Trust's monitoring and advocacy.

Methodology

The data contained in this report is broken down into the following sections: results from random sampling monitoring, results from Triaging of Serious Reportable Incidents, updates to our involvement with people through advocacy and a section focused on the manner of how deaths of people receiving services are handled.

This year Quality Trust began a project to monitor a statistically significant random sample of the 2293 people currently receiving services and supports. To attain the required level of certainty our sample will include 329 people. This will provide the most useful information to members of the City Council, families of people receiving services, providers and other advocates for people with developmental disabilities in the District of Columbia by producing results that are reflective of people receiving services. To further enhance the accuracy of our results we analyzed some basic demographic characteristics of the 2293 people; looking at gender, service funding, type of living arrangements and whether the person resided at Forest Haven. Although we will not report findings based on class status in our public reports, we will continue to note that information in our database. The characteristics of our sample match the larger group of people receiving services within two percentage points; well within the margin of error.

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Results from Quarter One Random Sample Monitoring

The following highlights are drawn from our review of 22 people during the period October 1, 2016 to December 31, 2016.

- 19 people are on the waiver, (86%)
- 10 people live in Supported Living, (45%)
- 8 people live at home with family, (36%)
- 11 people do not attend a day program, (50%)
- *7 people participate in Day Habilitation, (32%)
- *5 people participate in Employment Readiness, (23%)
- 7 people are between 21-30, (32%)
- 6 people are between 31-40, (27%)
- 5 people are between 51-60, (23%)
- 11 people required some type of assistance to answer questions (50%)
- 18 people had someone involved in their life who was not a paid staff person, (82%)
- 14 people reported that they go out to places they like, (64%)
- 21 of 22 people had a current ISP (95%)
- 85% of the ISP's contained goals which measured progress
- 82% of the goals were based on strengths, needs and preferences identified in assessments
- 68% of day program goals favored community rather than shelter based services
- 15 people use at least one piece of adaptive equipment, (68%)
- 12 of the 15-people's adaptive equipment was available for their use, (80%)
- The three highest health indicators noted this quarter are:
  - Bowel elimination problems 7 of 16 (44%)
  - Overweight 6 of 16 (37%)
  - Hypertension 5 of 16 (31%)
- 17 of 19 people had a current physical examination, (81%)
- 15 of 18 people had a current dental examination, (83%)
- 11 of the 13 Health Care Management Plans required contained all the person's healthcare needs, (85%)
- Direct Support Professionals involved in 9 of 11 HCMP's could describe their role (82%)
- 6 people had a restricted control implemented for which a Behavior Support Plan was necessary, (27%)
- We found documentation of required DDS approval for 3 of those plans, (50%)
- Of the BSP's we reviewed,
  - 50% clearly identified a replacement behavior
  - 83% used Positive Behavior Support strategies and techniques
- 12 people had a job or day program (55%)
- 13 of 21 people's Service Coordinator were completing required Monitoring Tools, (62%)
- Review of the required Monitoring Tools revealed that in 8 of 20 instances the Service Coordinator identified issues of concerns, (40%)

Conclusion

We cannot make any definitive or strong conclusions from the data collected in a single quarter. In general, the results are encouraging, however the lack of identified issues of concerns in the service Coordinator Monitoring Tools is noted. The value of these tools is derived from their ability to catch potential problems before they become serious. For that reason, we encourage leadership within the Service Planning and Delivery to continue its focus on improving performance in this area. So, while on its face only 50% participation in day programming could be a cause for concern, that concern is mitigated by the fact that most of those people reside at home with family and have requested day program services. Further, with only 23 reviews complete (7% of the total the will be completed), this is too small of a sample on which to base any overall analysis.

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Incidents and Investigations

During the first quarter of FY 2017 Quality Trust received 242 Serious Reports Incidents (SRI's). The following is a breakdown of those incidents by type.

Unplanned Emergency Inpatient Hospitalizations (UEIH) = 91 (38%)

Neglect =	46 (19%)
Serious Physical Injury (SPI) =	30 (12%)
Abuse =	27 (11%)
Exploitation =	22 (9%)
Death =	15 (6%)
Missing Person =	8 (3%)
Other =	3 (1%)
Total =	**242**

Understanding Serious Reportable Incident data:

The Developmental Disabilities Administration (DDA) of the Department of Disability Services (DDS) categories incidents per their seriousness and the risk they pose to people receiving service and supports. Significant incidents, those that cause potential for serious harm and/or loss of personal possessions through exploitation, are defined in policy as Serious Reportable Incidents. Those incidents characterized as presenting less harm are defined as Reportable Incidents. The list above represents the eight most numerous incident categories during the first quarter of FY 2017.

Unplanned trips to the hospital resulting in admission (UEIH), the 91 UEIH's are the single biggest category of Serious Reportable Incident. This trend has been evident in every quarter of every Fiscal Year since at least 2008. By comparison, during the first quarter of the previous Fiscal Year, Quality Trust received 264 SRI's, of which 113 (43%) involved unplanned trips to the hospital requiring admission. During the first quarter of FY 2015 the number was 249, 110 (44%) of which involved unplanned trips to the hospital requiring admission. So while it is a positive development that they 91 incidents represent a smaller percentage of all incidents in the first quarter, (36%), their overall dominance continues to be significant.

Every time a person is admitted to the hospital through an unplanned emergency room visit, the circumstances around the admission are investigated. Only two (1%) of the 91 investigations for unplanned hospitalizations completed by the Incident Management and Enforcement Unit (IMEU) were substantiated for neglect. It is of concern to us that DDS has not offered opinions to characterize the other 89 incidents.
The second highest category of incidents was neglect at 46 incidents. Of the 46 allegations of abuse, 19 (41%) were substantiated. No single provider accounted for more than four of the substantiated neglect incidents. It is interesting to note that while only 1% of UEIH's were substantiated for neglect, while 41% of non-hospitalization allegations of neglect were.

The data related to the number of deaths in the first quarter of the year is also highlighted. The 14 deaths in the first quarter of FY 2017 reflect a 100% increase from prior years. In the first quarter of both FY 2016 and FY 2015, there were 7 deaths. While such an increase in a single quarter is concerning, we also note that full Fiscal Year totals for

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deaths have remained consistent at approximately 33-36 deaths for the past several years. If the current pace were to continue unchanged for the remainder of the year it would result in approximately 60 deaths for the entire year, an increase of nearly 100%. We strongly recommend that DDS' Health & Wellness Unit (H&W) examine these 14 deaths to identify any patterns or trends that can be understood and addressed to minimize potential for harm.

Until the Columbus investigations have been received it is impossible to conduct an in-depth analysis, but we did a preliminary assessment of these 14 deaths. 11 of the people who died in the first quarter were men. Five people lived in ICF's/IDD, three received Supported Living services through the Home and Community Based Medicaid waiver, three people were residing in nursing homes or other long term acute care facilities and three people resided at home with family. The average age of the 14 people was 59 years old, and the median was 60 years of age. The youngest person was 24 at the time of death, and the oldest was 84 years of age. Two providers accounted for two deaths each, while the other ten were spread out among ten different providers. From our preliminary review, six people had experience a period of identified decline, while four of the reaming eight were somewhat unexpected. We were not able to definitively characterize the situation for the remaining four people.

We triaged 111 non-unplanned hospitalization incidents. Some highlights of our data tracking are:

- 31% were allegations of neglect
- 81% of neglect incidents identified provider Direct Professionals (DSP's) as the target
- 23% were allegations of abuse
- 76% of the targets in abuse incidents were removed from any contact with the person
- 22% were serious physical injury
- 76% of the serious physical injuries were attributed to accidents
- 18% were exploitation
- 32% of exploitation incidents identified provider DSP's as the target
- 34% of the people Triaged had at least one previous incident in the six months prior to our review

We triaged 65 unplanned hospitalization incidents. Some highlights from our results are:

- 44% of the people lived in Supported Living
- 28% lived in an ICF/IDD
- These findings are in line with our data which indicates that Supported Living is the most utilized residential service, and ICF/IDD is the second most popular
- 21% lived in their Natural Home with family
- 80% had nursing support as a feature of their residential services and supports
- 69% had experienced 1-3 prior incidents for unplanned trips to the hospital
- 30% Had experienced no prior incidents for unplanned trips to the hospital
- Only 5% were psychiatric in nature
- 38% had been hospitalized for the same condition within six months of the incident
- The following conditions were noted on the SRI:
    - 18% breathing difficulties
    - 18% vomiting

DDS policy requires that all Serious Reportable Incidents be investigated by either the provider with oversight by DDA, or by DDA on their own. Of the 243 SRI's reported in the first quarter, 117 required a completed investigation by the end of quarter one. Of those only one was completed late, and that report was only one day past due.

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Conclusion

Overall incident data has remained remarkably stable except for the number of deaths recorded. We urge DDA, through all its many units; Service Coordination, Health & Wellness, Quality Management and Incident Management and Enforcement to remain vigilant and closely track this data for the remainder of the year. The goal of this tracking would be to proactively implement any interventions needed to ensure the health and well-being of people receiving serviced and supports.

Advocacy

This quarter has seen a surge in the number of people receiving active advocacy from the Quality Trust. During the first quarter of FY 2016 there were 14 people being supported, during this first quarter of FY 2017 there are 31 people receiving advocacy supports. There was also an increase in outcomes met from 11 during the first quarter last year to 16 this year. Another change from the previous year is the increase in the number of outcomes relating to changes/supports in residential placement. 50% of all referrals are for support with residual issues. There were 2 last year and 8 this year. Other outcomes were similar in numbers and included the outcomes listed below.

Two people were closed without their outcomes being met. One person died and one person was homeless and had no way to meet or communicate with QT staff. There were no referrals to our legal team and only one child was referred to our Resource Specialist.

Referral sources are consistent with previous years except for people referring themselves. Last year during this quarter there were no self -referrals and this year there were two.

People in active advocacy: 31

People referred to legal: 0

People's outcomes met or closed: 16

Children's advocacy: 1

Number of Outcomes Met	Outcome
8	Residential move or supports
1	Family concerns resolved
1	Accepted into DDS
1	Medical Appointments scheduled and followed up on
1	Accepted into RSA
1	Person died
1	Worked on documentation for a DDS appeal and could not find it.
1	Links to pregnancy/parenting supports
1	Person was homeless with no way to make contact. Unable to continue.

Referral Source	Number of referrals
The person needing support	2
Family	1

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Provider	1
QT Attorneys	2
DDS SC	2
QT monitoring	2
Outside agency	1 (hospital SW)

LTAC Follow Up

We met 8 people in long term care this quarter. Reasons for placement and the number of people are consistent with previous quarters and include the need for physical therapy, IV antibiotics and wound care. There was only one instance where we felt a person was not placed in the least restrictive setting. He is a young man who has lived in a children's hospital since he was 10 due to trauma from an abusive family. He will be aging out of school and into adult services in the spring of 2017. He will move from the hospital at that time and into a community residence. Two people we met eventually died.

Our monitoring of activity over the past quarter continues to indicate that DDS is meeting its requirements in this area by: making proper notification of proposed placements, sending Service Coordinators or clinical staff to follow people once placed, holding discharge meetings, and completing monitoring when the person returns home. LTAC follow up visits were higher this quarter (8) than the 1st quarter of FY 2016, which had only 2 LTAC follow ups.

Reasons for LTAC
PT-2
Skin ulcers/dementia
Rehab from a fall/traction
Antibiotics for UTI
Wound care-2
Living in nursing home until he graduates

SRI Follow Up

Serious reportable incident follow-up continued this quarter, with visits to 8 people. The Quality Trust nurse completed 3 follow ups; 2 for UEIH incidents and 1 for a medical neglect. Two of those visits produced emails to DDS regarding specific concerns, and one visit led to individual monitoring of everyone in the home. One abuse follow up was done for a person living in a natural home, and that person was referred to Adult Protective Services.
The number of SRI follow up visits completed during the first quarter this year (8) was an increase over the 2 completed in the first quarter of FY 2016.

Incident type
Abuse-3
SPI-1
UEIH-3
Neglect-1

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Conclusion

Overall we have seen increased numbers in all categories of follow up (advocacy, SRI follow up and LTAC follow up) from the same time last year. Although most of the types and reasons for follow up are consistent with previous numbers, there was a large increase in need for advocacy concerning residential placement.
There has also been a large increase in the number of LTAC placements, which may also correlate to the increased (100%) number of deaths this quarter as compared to the same quarter from last year. Given this data, we recommend that DDS continue to closely monitor people with high number of incidents, especially those with multiple UEIH incidents and those placed in long term acute care.

RCRC Review:

Quality Trust's reviews and analyzes the data from the meeting minutes of the Restrictive Control Review Committee ("RCRC"), which reviews behavioral support plans to ensure restrictive controls within them are appropriately justified. These minutes are provided by DDS monthly.

Based on that review, during the first quarter of Fiscal Year 2017:

- The RCRC reviewed a total of 184 Behavioral Support Plans ("BSPs") for 171 people.
  - The majority of reviews were identified as non-emergency reviews of new BSPs (114; 62%) and updated BSPs (29, 16%)
  - 4 BSPs (2%) were identified as being reviewed on an emergency basis.
  - 37 BSPs (20%) were not specifically identified in the minutes as new or updated.

- Of the BSPs reviewed, 159 (86%) were approved, 3 (2%) were approved for 90 days only, 2 (1%) were approved for 2 years, and 1 (less than 1%) was approved for 6 months only.
  - 69 (38%) of these BSPs were approved even though the RCRC minutes included substantive comments requiring the revision of the BSP and/or raising issues that called into question whether the BSP met the 8 required criteria listed in DDS' RCRC Procedure.[1]
  - 2 BSPs were approved without the RCRC minutes including answers all of the 8 required criteria listed in Section 3(D)(3) of DDS' RCRC Procedure.
  - 1 BSP was approved even though the RCRC concluded the BSP did not meet at least 2 of the 8 required criteria listed in the DDS' RCRC Procedure.

- 3 (2%) of the BSPs were rejected.

- 16 (9%) of the BSPs were deferred.
  - 13 of these BSPs (7%) were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 criteria listed in DDS' RCRC Procedure.

- The three most common restrictive controls reviewed were the use of psychotropic medications (within 169 or 92% of the BSPs), behavioral one-to-one aides (within 62 or 34% of the BSPs), and the physical restraint (within 18 or 10% of the BSPs).

- The RCRC reviewed 4 requests for exemption from the requirement of having a BSP, all were approved.

[1] See DDS Procedure No. 2013-DDA-PR014, Section 3(D)(3), available at https://dds.dc.gov/node/739062. These 8 criteria include: (1) Does the BSP include targeted behavior that is consistent with the person's diagnosis? (2) Does the BSP include relevant data collection? (3) Does the BSP include demonstrated review of the data by the psychologist? (4) Does the BSP include procedures to address behavioral issues consistent with DDA policies? (5) Does the BSP include a functional analysis? (6) Are there proactive, positive strategies identified in the BSP? (7) Is there a rational for using the restrictive interventions? (8) Are there benchmarks for reducing the restrictive interviews including a titration plan for medications (or statement of lowest effective dose based on prior attempts to reduce)?

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As noted in our prior reports, we have seen improvements made to the RCRC processes, as reflected in its minutes and in response to our prior recommendations. For example, within the prior fiscal year, consistent with its own published guidance,[2] the RCRC began using a "Yes, with recommendations" designation, when it determined a BSP met one of the 8 criteria in the DDS RCRC Procedure, but had further recommendations for improvements that should be made to the BSP. The DDS Rights and Advocacy Specialists (RAS) also began to use a more detailed RCRC review template within its minutes, which provided clarity that facilitated QT's review. However, during the last month of first quarter of this fiscal year, we noted a backslide in terms of this practice. For example, the "Yes, with recommendation" designation generally stopped being used and frequently not all the entries within the RCRC template were completed. We would ask that DDS direct the RAS to conform to its prior level of detail within the minutes.

Moreover, we are concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- 51 BSPs (28%) were approved until the end of the person's current or next ISP year, even though the RCRC minutes also indicated that the BSPs should be revised and re-submitted for an updated review prior to that time.
- 29 BSPs (16%) were approved even though they included a restrictive control for which the RCRC requested further justification.
- 9 BSPs (5%) were approved even though they included a restrictive control that the RCRC expressly rejected or deferred a decision on.

In such cases, it would appear to be more consistent with the intent of its procedures for RCRC to reject or defer the BSP to ensure that that the person's team does not implement the unrevised BSP that contains elements the RCRC found problematic and/or unjustified.

HRAC Review:

Quality Trust reviews and analyzes the data from minutes of the Human Rights Advisory Committee ("HRAC"), which reviews human rights issues arising within the DDA system. During this quarter, DDS provided us with two sets of HRAC minutes covering October and November 2016. DDS informed us that the HRAC did not convene in December 2016.

Based on those minutes, during this quarter, the HRAC reviewed 13 human rights issues for 12 people.

- 5 (38%) of these issues were about Long Term Acute Care ("LTAC") placements, 2 of which were new reviews and 3 of which were updated reviews of continued placements.
- 4 (31%) of these issues were about nursing home placements, 1 of which was a new review and 2 of which were updated reviews of continued placements.
- 3 (23%) of these reviews were annual reviews of out-of-state placements.
- 1 (8%) review was about a court-ordered placement at St. Elizabeths Hospital.

In response to our past recommendations, HRAC is now generally documenting in its minutes whether it is approving, disapproving, or deferring "out-of-state" placements. For clarity's sake, it also should consistently take that approach for all placements it reviews, including all LTAC and nursing home placements. For example, in one case this quarter, the HRAC did not clearly "disapprove" of an LTAC placement where the person was no longer receiving the active treatment that had made it the most appropriate placement in the first place.

In addition, when the HRAC finds that a placement is the "most appropriate" or the "least restrictive," it should consistently document within its minutes why it reached that conclusion. For example, in one case, the HRAC found that continued LTAC placement was "the most appropriate," even though the minutes reflect that there was a "delay"

[2] See DDS Guidance for RCRC Review of Behavioral Support Plans, *available at* https://dds.dc.gov/node/803762.

in the person transitioning back to his home because supplies and durable medical equipment had to be ordered and approved by Medicaid. Such a "delay" could indicate a DDA systems problem was preventing the person from living in the community and raises a “red flag” indicating that he may not, in fact, be currently living in the least restrictive placement appropriate to meet his needs. In another case, the HRAC found that an out-of-state placement was the "most appropriate placement," even though the DDS SC missed the last two quarterly monitoring visits and, thus, the evidence informing the HRAC deliberations could arguably be out-of-date.

Summary:

During the first quarter of FY 2017, the judge in the Evans v. Bowser class action litigation ruled that the District had substantially met the requirements of the 2001 (and updated 2010) Plan for Conclusion. In January of 2017, the Parties to the case filed a motion to dismiss all outstanding court orders, and the case came to an end on January 10, 2017. This is an important advance in the system that serves people with developmental disabilities in the District of Columbia.

Reaching this goal now allows the city to focus its attention on the larger landscape of funding and administering supports and services at the state level. It is vitally important the system is optimized so that as regulatory or funding expectations shift, these changes will add to, rather than detract from the ability of the District to gather and analyze large amounts of both qualitative and quantitative data. It is also important to note that while the conclusion of the Evans case is an important milestone, further progress will require that the District of Columbia achieve more than compliance. People who use supports and services in 2017 have expectations for more than congregate living and day program arrangements. Services that are individualized and meaningfully tailored to the person’s preferences and needs must become the norm in the DD system of the very near future. The Centers for Medicaid and Medicare Services (CMS) requirement that states develop plans to bring about further individualized planning which grants service recipients and the supports greater control over the services they receive underscores this point. In sum, while much has been accomplished, much more is required to develop and sustain the array of individualized models required to meet the needs of people in 2017 and beyond.