



## **2nd Quarter Data**

(January 1, 2018- March 31, 2018)

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

This is our fifth quarter of gathering data regarding compliance with court orders in the *Evans* case. We are reaching the end of the work; having completed 288 of the required 309 reviews required to arrive a statistically significant finding about the quality of services provided to the approximately 2300 people in the DD system in the District of Columbia. Through five quarters our findings indicate compliance is being maintained. At the same time, these five quarters have provided numerous situations where the system underperformed for individual people.

A milestone was reached on January 7<sup>th</sup>, 2018. That was the one-year anniversary of the conclusion of the *Evans* case. With that milestone reached it is time for the District government to move beyond the compliance model that served it well in exiting the case. It is now incumbent for all District government agencies involved in the provision, licensing & regulation and funding of DD services to reach toward a higher goal. In this report we will provide examples that point to the need for a greater commitment to looking at people one at a time, rather than as members of various groups, for it only through such individualized focus that truly positive outcomes will be reached for everyone on the system.

## Individual Monitoring

### Monitoring

**Total number of monitoring assessments sent to DDS: 71**

**Total number of people monitored who had a nursing review: 62**

**Total number of people monitored through two quarters: 119**

### Demographics

- 77% (54) waiver
- 23% (17) not on the waiver
- 18% (13) ICF
- 42% (30) Supported Living
- 8% (6) Residential Habilitation
- 6% (4) Host Home
- 25% (18) natural home
- 39% (28) had no day program
- Demographically, the largest age group was 31-40, %
- 61% (43) were male
- 39% (28) were female
- 73% (52) walk without assistance
- 73% (52) communicate using words
- 87% (62) had relationships with people other than paid staff

### Staff Training

- 80% (52/65) of residential staff had all required trainings
- 78% (35/45) of day staff had all required trainings
- 69% (37/54) had a day DSP that could describe their health-related responsibilities (Not all people have staff support.)
- 88% (42/48) had a day DSP that could describe their responsibilities (Not all people have staff support/day program.)
- 89% (57/64) had a residential DSP that could describe their responsibilities. (Not all people have staff.)
- 65% (34/52) had staff that were knowledgeable of intended effects and side effects of medication (Not all people had staff and or medication, (e.g. natural homes, independent living)

### Medical/Nursing Profile

- 3% (2/62) had choking precautions in place
- 50% (31/62) had bowel elimination problems
- 42% (26/62) had a seizure diagnosis
- 23% (14/24) had hypertension
- 10% (6/62) had diabetes
- 24% (15/62) were overweight

Behavioral Health/Use of Psychotropic Medications

- 58% (41/71) took no psychotropic medications
- 10% (3/30) took 1 psychotropic medication
- 50% (15/30) took 2 psychotropic medications
- 20% (6/30) took 3 psychotropic medications
- 10% (3/30) took 4 psychotropic medications
- 7% (2/30) took 5 psychotropic medications
- 3% (1/30) took over 5 psychotropic medications

Use of Neuroleptic Medication

- 59% (42/71) took no seizure medications
- 69% (20/29) took 1 seizure medication
- 21% (6/29) took 2 seizure medications
- 4%(1/29) took 3 seizure medications
- 7% (2/29) too more than 3 seizure medications

Follow -up on medical recommendations

- 86% (25/29) had recommendations from the PCP implemented (only 29 people had recommendations from their PCP.)
- 96% (23/24) had dental recommendations implemented (only 24 people had recommendations made by their dentist,)
- 87% (27/31) had a HCMP that referenced all their health needs (Natural homes are not required to have HCMP)

DDS Service Coordinator Performance

- 38% (27/71) DDS Service Coordinators ensured the delivery of services outlined in the ISP
- 61% (36/59) identified issues in monitoring tools (not all people had obvious issues that required identification.)
- 80% (57/71) completed monitoring tools as required

**Advocacy**

People in active advocacy: 20

Outcomes Met or Closed: 17

New Referrals: 18

<b>Number of Outcomes Met</b>	<b>Outcome</b>
6	Residential move/residential issues resolved
4	Closed by the person/family/changed their minds

1	Heat in the home resolved
1	RSA in place
1	Change in day program
1	Financial issues resolved
1	Psychiatric supports changed/put in place
1	Medical recommendations completed
1	DDS application

**LTAC Follow Up**

**Number of LTAC follow Up Visits: 5**

- We received notification from DDS of 4 people going into LTAC. That is 100% notification.
  - 2 people received ongoing advocacy.

Reason for LTAC (note that people have multiple reasons)	Number of people
Antibiotics	3
Accident rehabilitation	1
Being transferred for residential placement	1

**SRI Follow Up**

**Total SRI follow-up: 11 assigned**

Incident Type	Number
<b>UEIH</b>	<b>3</b>
<b>Neglect</b>	<b>3</b>
<b>Abuse</b>	<b>2</b>
<b>SPI</b>	<b>1</b>
<b>Missing Person</b>	<b>1</b>

**UEIH:**

- 3/3 (100%) people that had UEIH had recommendations made at the time of discharge. 3/3 people (100%) had the recommendations completed at the time of the visit.
- people (%) had been discharged back to their home at the time of the visit. One person went to LTAC.
  - 3/3 people (100%) had started back at their day program at the time of the visit.
    - No new SRIs were generated after the visit.

**Non-medical follow up:**

- All people were deemed to be safe after the visit.

- 3/5 (60%) people had multiple incidents in the same category, and 2/5 (40%) had plans developed to help reduce future incidents.
  - No new SRIs were generated after the visit

### Incidents

During the second quarter of FY 2018 Quality Trust received 393 Serious Reportable Incidents, (SRI's), an increase of 71 incidents, or (+26%) from the first quarter of 2018. The following is a breakdown of those incidents by type.

#### **Breakdown of incidents and percentages Q2 2018**

<b>Incidents Q2 2018</b>	<b>Total Incidents</b>	<b>Percentage of total</b>
Unplanned Emergency Inpatient Hospitalizations	153	(39%)
Neglect	88	(22%)
Serious Physical Injury	64	(16%)
Abuse	42	(11%)
Exploitation	11	(3%)
Death	9	(2%)
Missing Person	16	(4%)
Other types	10	(3%)
<b>Total</b>	<b>393</b>	<b>(100%)</b>

#### **Breakdown of incidents and percentages Q1 2018**

<b>Incidents Q1 2018</b>	<b>Total Incidents</b>	<b>Percentage of total</b>
Unplanned Emergency Inpatient Hospitalizations	112	(36%)
Neglect	75	(24%)
Serious Physical Injury	48	(15%)
Abuse	35	(11%)
Exploitation	15	(5%)
Death	14	(4%)
Missing Person	8	(3%)
Other types	6	(2%)
<b>Total</b>	<b>313</b>	<b>(100%)</b>

#### **Non-Medical Incidents**

- Abuse-5/42 had multiple abuse incidents, 39/42 were determined to be safe, 3 people were followed up on.
- Serious physical injury- 15/64 sustained their injury during a behavioral episode. 11/15 had a current BSP. 1/15 was injured during a seizure.
- Neglect-35/88 involved medical care, 82/88 were deemed safe, and 6 people were followed up on.

## **Medical Incidents: Many people are admitted with several conditions**

- 30/153 (20%) lived in their natural homes
- 75/153 (49%) lived in supported living
- 44/153 (29%) lived in an ICF
- 3/153 (2%) lived in res hab
- 128/153 (84%) incidents were medical in nature and had one or more of the following diagnosis at the time of admittance.
- 17/128 (13%) had a UTI
- 39/128 (26%) had pneumonia
- 65/128 (51%) had breathing problems
- 14/128 (11%) had constipation issues
- 21/128 (16%) had g-tube issues
- 60/128 (47%) had seizures
- 43/128 (34%) were vomiting
- 115/128 (90%) had no previous UEIH incidents within the last 6 months, 14/153 (11%) had between multiple incidents in the previous 6 months.
- 25/153 (16%) of UEIH incidents were psychiatric. 6/25 (24%) were seen at CPSP, 19/25 (76%) had approved BSP supports in MCIS
- 16/25 (64%) had 911 called

## **Investigation Reviews**

- 31 investigations reviewed
- All 31 investigations were for UEIH
- 30/31 contained recommendations
- Did the dates in MCIS and the provider investigation match?
  - 24/31 (77%) did
  - 6/31 (19%) did not
  - 1/31 (3%) was N/A
- Was a follow up appointment recommended?
  - 19/31 (61%) did recommend a follow up appointment
  - 12/31 (39%) did not
- If there was a follow up appointment recommended; was it completed on time?
  - 16/19 (84%) were on time
  - 3/19 (16%) were not on time
- All recommendations for training were completed on time (9/9, 100%)

## **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 generally provided by DDS monthly.

Based on that review, during the first quarter of Fiscal Year 2018:

- The RCRC reviewed a total of 164 Behavioral Support Plans (“BSPs”) for 146 people.
  - Most reviews were identified as non-emergency reviews of new BSPs (130; 79%) and updated BSPs (33; 20%).
  - 1 BSP was identified as being reviewed on an emergency basis.
- Of the BSPs reviewed, 141 (86%) were approved.
  - 40 (24%) of the 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.<sup>1</sup>
- 3 (2%) of the BSPs were rejected.
  - 20 (12%) of the BSPs were deferred.
    - 18 of these BSPs were deferred, rather than rejected, even though the RCRC answered “No” to one or more of the 8 required criteria listed in DDS’ RCRC Procedure.<sup>2</sup> More specifically, RCRC found:
      - In 7 cases, the BSP did not include procedures to address behavioral issues consistent with DDA policies.
      - In 6 cases, the BSP did not include targeted behavior that was consistent with the person’s diagnosis.
      - In 5 cases, there was not a rationale for using the restrictive interventions
      - In 4 cases, there were not benchmarks for reducing the restrictive interventions, including a titration plan for medications, or a statement of lowest effective dose based on prior attempts to reduce.
      - In 4 cases, the BSP did not include relevant data collection.
      - In 1 case, the BSP did not include demonstrated review of the data by the psychologist.
      - In 1 case, the BSP did not include a functional analysis.
      - In 1 case, there was not a rationale for using the restrictive interventions.
    - In 10 of these deferred cases, RCRC found that two or more of the required criteria were not met. Yet, RCRC still did not reject the BSPs.
      - The five most common restrictive controls reviewed were the use of psychotropic medications (within 158 or 96% of the BSPs), behavioral one-to-

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<sup>1</sup> See DDS Procedure No. 2013-DDA-PR014, Section 3(D)(3), available at <https://dds.dc.gov/node/739062>, which lists the 8 criteria. Under Section 3(D)(4)(a) of this Procedure, to approve a BSP, the Committee must find that a BSP meets all of these 8 criteria and “meets professional standards.”

<sup>2</sup> Under DDS Procedure No. 2013-DDA-PR014, Section 3(D)(4)(c), RCRC “shall reject” a plan when it does not meet[] the criteria discussed above at [Section 3] D.3” (emphasis added).

one aides (within 68 or 42% of the BSPs), physical restraint (within 15 or 9% of the BSPs), “sharps restrictions” (within 12 or 7% of the BSPs), and medical sedation (within 10 or 6% of the BSPs).

- The RCRC reviewed 12 requests for exemption from the requirement of having a BSP. All were approved.

As noted in our prior post-compliance reports, we had seen improvements made to the RCRC processes, as reflected in its minutes and in response to our prior recommendations. However, we are concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- 32 BSPs (20%) were approved until the end of the person’s current or next ISP year, even though the RCRC minutes also indicated that the BSPs must be revised and re-submitted for an updated review prior to that time.<sup>3</sup>
- 28 (17%) of the BSPs were approved, even though they referred to a restrictive control that the RCRC expressly rejected, deferred approval, or required further justification for.

As we have indicated in our past reports, 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 analyzes the data from minutes of the Human Rights Advisory Committee (“HRAC”), which reviews human rights issues arising within the DDA system. For the first quarter, DDS provided us with the minutes from HRAC meetings held on October 6, October 13, October 25, November 22, December 14, and December 22, 2017.

Based on the minutes provided, during the first quarter, the HRAC reviewed 61 human rights issues for 33 people.

- 5 issues were reviewed on an emergency basis.
- 36 issues were about Long Term Acute Care (“LTAC”) placements.
- 11 issues were about nursing home placements.
- 9 issues were about out-of-state placements.
- 2 issues were about the use of an audio monitor.
- 1 issue was about alcohol addition
- 1 issue was about a dispute surrounding requesting a BSP exemption
- 1 issue was about single occupancy housing

This quarter, HRAC had difficulty establishing a quorum of members required to vote to make recommendations. Quorum was not established for the meetings on October 6, October 13, and December 27, 2017.

- 30 issues were reviewed without quorum.

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<sup>3</sup> Under the DDS Guidance for RCRC Review of Behavioral Support Plans, available at <https://dds.dc.gov/node/803762>, BSPs that RCRC approves are supposed to be “acceptable as written and do not require further revision.”



- 12 of those issues were voted on without quorum, including updates on existing nursing home and LTAC placements and other human rights issues.

Given the data above, we will focus our recommendations this quarter on this quorum issue, as it impacts the ability of HRAC to properly and timely review and vote on human rights issues that have a deep impact in the lives of people with disabilities supported by DDA. Under DDS Procedure, HRAC is required to make recommendations only when there is a quorum.<sup>4</sup> Based on the HRAC minutes, the difficulty in establishing quorum appears to be linked to the HRAC not having enough external (non-DDS) members present at the meeting. Under DDS procedure, for non-emergency reviews, a quorum is a simple majority of members, where the number of external members is greater than the internal members.<sup>5</sup> For emergency reviews, a quorum is at least 3 members, at least one of whom is an external member.<sup>6</sup>

We understand that DDS is in the process of revising its HRAC Procedure and are concerned that it may seek to solve this quorum problem by lessening the requirements around external member presence at meetings. If it does do so, DDS will be diluting the human rights protections afforded to the people it serves. The existing quorum requirements recognize the importance of having the perspectives of people who receive supports and services from DDA, their family members, and others who are not employed by DDS. Such perspectives promote a system of checks and balances that is critically needed, given the role with which HRAC is tasked within the DDA system. DDS should instead focus its efforts on recruiting more external members for HRAC from members of Project ACTION!, the Developmental Disabilities Council, DDS' Communities of Practice, and family groups and networks.

### **Conclusion**

With five quarters of data behind us since the conclusion of *Evans v. Bowser*, our data has consistently shown that in the main compliance with the court orders left behind are being met. We will have accumulated enough data by the mid-way point of the third quarter to wrap up this work, and will distribute the overall findings of seven quarters of monitoring results. The data have remained remarkably consistent throughout this project, that is, where results were high in each area, they remain so and where they were lower, they have remained there as well. One exception is the in DDS Service Coordinator's ensuring that all services listed in the ISP are being delivered where findings fell once we began to utilize a stricter standard for compliance. As we have noted previously, while it is a positive development that overall compliance numbers are high, we continue to encounter significant substandard services at the individual level. These instances are cause for great concern.

At least since 2008 we have voiced our concerns with the number of people experiencing unplanned hospitalizations. Only recently has DDA begun to look at the issue. We are undertaking an analysis through our next monitoring project, and will provide more details in our final monitoring report dealing with these areas of compliance with the court orders in the *Evans* case.

We are also modifying our monitoring and advocacy protocol. The bullets below note our current process and the changes we are making to it.

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<sup>4</sup> DDS HRAC Procedures, Procedure No. 2013-DDA-H&W-PR012, at Section 3.A.3.b, available at <https://dds.dc.gov/node/738902> (eff. September 3, 2013).

<sup>5</sup> DDS HRAC Procedures, at Section 3.A.3.b.

<sup>6</sup> DDS HRAC Procedures at Section 3.A.4.b.i..

