

Quarterly Monitoring Summary

October 1, 2018 – December 31, 2018

Introduction

This is the first quarterly monitoring and lay advocacy report for FY 2019. The report, covering October 1, 2018 to December 31, 2018 describes Quality Trust's efforts to ensure the adequacy of services and supports for the approximately 2400 people in the District of Columbia's developmental disabilities system. The report also includes details regarding the requests for lay advocacy received, and their outcomes.

We have also begun a monitoring project focused on Unplanned Inpatient Emergency Hospitalizations (UEIH). The focus of the analysis are the antecedents, outcomes, follow up, and investigation of a statistically significant random sample of incidents that occurred in FY 2017. Our hope is to provide DDS & DHCF, City Council committees, providers, people with disabilities, and their families insight on:

- How nursing services are organized across living arrangements
- Whether there are gaps/lapses in those services
- The extent to which effective coordination and cooperation exists between provider nurses, doctors in private practice, hospitals, and Long-Term Acute Care Facilities (LTACs)
- The effectiveness of monitoring follow-up and coordination done by Service Coordination
- Insight into the possible explanations for the high percentage of non-cause finding dispositions within investigations, e.g., "resolved-no neglect or abuse found," inconclusive, unsubstantiated, administrative closure
- Recommendations for possible alterations in current policy and practice if warranted

We will engage stakeholders in the IDD community in robust discussions about our findings once our work is complete.

Lay Advocacy

During the first quarter of the Fiscal Year there were forty (40) people supported through lay advocacy. There were seventeen (17) outcomes met, and four (4) people who decided not to continue. One (1) person lacked proper documentation for his desired outcome, and three (3) people did not follow up or choose to continue.

There were fourteen (14) new referrals. The main source of referrals came from family members 6/14 (43%). Referrals also came from providers 2/14 (14%) and outside agencies 2/14 (14%). Other referrals came from DDS 1/14 (7%) and from within Quality Trust's internal triage process 2/14 (14%). There was also one (1) person (7%) who called himself. Quality Trust navigators and nurses are assigned follow up visits on certain Serious Reportable Incidents (SRI) and Long-Term Acute Care (LTAC) placements. If after making these initial visits QT staff are concerned, they continue to support the person through advocacy. This quarter two (2) visits resulted in further action through advocacy. One (1) came from a long-term care visit and another from a Serious Reportable Incident follow up.

The new advocacy referrals included the following desired outcomes;

- One (1) person wanted to move

- Two (2) people had issues with roommates
- One (1) person had family issues
- One (1) person wanted help because RSA was not meeting their needs
- Two (2) people needed support to get into DDA services
- One (1) person needed In-Home Supports
- One (1) person required a modification to their home
- One (1) person needed legal and financial supports
- Two (2) people needed help from someone who spoke Spanish (our bilingual staff assisted that person)
- One (1) person needed assistance understanding RSA, -specifically how to access college scholarships
- One (1) parent needed resources for her child with a disability

Outcomes included: Five (5) people moving, two (2) people acquiring waiver services, one (1) referral to counseling, one (1) referral for legal/financial support, one (1) person was provided futures planning and seven (7) nursing outcomes were provided by our nurses.

Often, we see a person several times over the course of a year. For example, we met Mr. C. when we received a Serious Reportable Incident for neglect in which he was the alleged victim. Upon further investigation, it was noted that the provider had several incidents involving neglect within a short period of time, so a navigator was assigned to follow up. Those issues were resolved. Later the provider contacted us and asked that we provide advocacy to Mr. C. because their relationship with his family was deteriorating. Advocacy improved that situation, but then Mr. C. was placed in a LTAC, where we met him again. Over the course of three months, we had three distinct interactions with him; Serious Reportable Incident follow up, advocacy and LTAC follow up.

We also met Ms. S. She was placed in a LTAC where we first met her. Several months later, she had an unplanned emergency inpatient hospitalization, and a Serious Reportable Incident follow up visit was initiated through the triage process. She went back to the hospital approximately four months later and another visit was made. This time, Ms. S was placed in hospice care, and the QT staff assured she was receiving appropriate palliative care.

LTAC:

During the first quarter of the Fiscal Year there were ten (10) notifications of Long-Term Acute Care Placements (LTACs). One person never went to LTAC and instead was able to go straight home from the hospital. The LTAC facility most used was Bridgepoint (3/9 or 33%) and then Carroll Manor (2/9 or 22%).

People often needed more than one therapy while in LTAC. They most often need Physical Therapy (6/9 or 67%) and Occupational Therapy (4/9 or 44%). People also needed IV antibiotic care, tracheostomy care, ventilator weaning, and skilled nursing.

QT monitors visit people while in the LTAC and again after they return home to ensure that all discharge recommendations are met. If there are ongoing concerns, we continue our support through lay advocacy. That scenario occurred two (2) times this quarter. Based on our follow ups, there were no concerns that people should be placed in a less restrictive setting.

SRI follow up:

There were fourteen (14) Serious Reportable Incident (SRI) follow-up visits made during the first quarter. Once again, concerns for people experiencing an Unplanned Emergency Inpatient Hospitalization (UEIH) were the most numerous categories of SRI follow up, with eight (8) of the people (57%) being assigned to a QT monitor. We followed up after four (4) incidents of neglect, and two (2) incidents involving allegations of abuse. QT staff met with all fourteen (14) people requiring our assistance.

Of the eight (8) people hospitalized, seven (7) reported feeling better. All eight (8) had discharge recommendations, and all recommendations were either completed or scheduled at the time of our follow-up visit. We deemed four (4) people (29%) to be at risk based on our initial follow up, so our nurses continued to follow them until they were certain recommended interventions were completed. Those interventions included follow-up regarding weight loss for two

people, a new g-tube placement, ensuring improvements in wound care, renewed training for staff for specific medical interventions, as well as development of a psychiatric evaluation and its inclusion in the person's amended Individual Service Plan (ISP).

In both allegations of abuse, staff were removed and placed on administrative leave. In all cases of alleged neglect, the staff were retrained. We deemed the six (6) people who had either abuse or neglect incidents were free from harm at the end of our follow up.

Serious Reportable Incidents and their Investigations

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect)	Percent substantiated	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)				Percent not substantiated				
				150	26	28	14	55%	9%	10%	5%	Total= 79%
309	274	43 + 10 +2	21%	150	26	28	14	55%	9%	10%	5%	Total= 79%

Breakdown of Serious Reportable Incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	100	36%	1% (1 of 100)	99% (99 of 100)
Neglect	61	22%	52% (32 of 61)	48% (29 of 61)
Serious Physical Injury	43	16%	9% (4 of 43)	91% (39 of 43)
Abuse	29	11%	24% (7 of 29)	76% (22 of 29)
Missing Person	13	5%	8% (1 of 13%)	92% (12 of 13)
Exploitation	12	4%	42% (5 of 12)	58% (7 of 12)
Serious Medication Error	8	3%	13% (1 of 8)	87% (7 of 8)
Inappropriate use of restraints causing injury	3	1%	67% (2 of 3)	33% (1 of 3)
Other	3	1%	33% (1 of 3)	67% (2 of 3)
Use of approved restraints	1	<1%	0% (0 of 1)	100% (1 of 1)
Death	1	<1	N/A	N/A

HRAC Review:

Quality Trust analyzes the data from minutes of the Human Rights Advisory Committee ("HRAC"). This committee reviews human rights issues arising within the DDA system. During the first quarter of fiscal year 2019 DDS provided us with the minutes from HRAC meetings held on October 24, 2018; November 28, 2018; November 30, 2018; December 11, 2018; and December 19, 2018.

Based on the minutes provided, the HRAC reviewed forty-one (41) human rights issues for twenty-five (25) people during this quarter.

- 22 issues (54%) were about Long-Term Acute Care ("LTAC") placements.
- 5 issues (12%) were about out-of-state residential placements
- 3 issues (7%) were about nursing home placements.
- 5 issues (12%) were about restrictions, including those relating to behavioral one-to-one aids, door alarms, psychotropic medication titration, and those in revised BSPs.
- 6 issues (29%) were about other human rights concerns, including requests for exemption from fire drills, request for one-bedroom units, requests to be supported by particular staff, and refusal to go to medical appointments or provide medical documentation to their providers.
- 3 issues (7%) were reviewed on an emergency basis.

In our prior reports, we have recommended that DDS recruit more external members to serve on HRAC, given the past difficulties it has had in establishing the quorum of members required to vote on recommendations. Therefore, we are pleased the minutes indicate that DDS successfully recruited two additional external members to join HRAC this quarter.

In terms of recommendations for improvements to the HRAC process, we urge HRAC not to approve people's continued placements in LTACs and nursing homes without receiving a monthly update from the DDS Service Coordinator. Such approvals occurred in at least three (3) reviews this quarter. If there is no update for HRAC to review, it is unclear how it can properly determine whether that placement remains the least restrictive and most appropriate for the person.¹ In such cases, it would be more consistent with DDS Procedure for HRAC to defer its determination until it receives an update.²

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 ("BSPs") of people served by DDA to ensure restrictive controls within them are appropriately justified. These minutes are generally provided by DDS monthly.

Based on Quality Trust's review, during the first quarter of Fiscal Year 2019:

- RCRC reviewed a total of one hundred seventy-seven (177) BSPs for one hundred fifty-nine (159) people.
 - All the reviews appeared to be non-emergency reviews of new BSPs (140; 79%) and updated BSPs (37; 21%).
- Of the BSPs reviewed, 171 (97%) were approved. A subset of these BSPs were approved for 30 days only (6 BSPs), 90 days only (10 BSPs), and 180 days only (5 BSPs).
 - 49 (28%) 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 approval criteria listed in DDS' RCRC Procedure.³
 - 1 of the BSPs was approved without RCRC's answers to the 8 criteria being included in the minutes.
 - 11 of the BSPs were approved with RCRC answering both "Yes" and "No" to the criterion about whether the BSP includes relevant data.
- 1 (0.6%) of the BSPs were rejected.
- 5 (3%) of the BSPs were deferred.
 - 2 of the BSPs were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 required criteria.⁴ More specifically, RCRC found:
 - In 1 of these cases, the BSP did not include procedures to address behavioral issues consistent with DDA policies.
 - In 1 of these cases, the BSP did not include a rationale for using the restrictive interventions
- The five most common restrictive controls reviewed were the use of psychotropic medications (within 174 or 98% of the BSPs), behavioral one-to-one aides (within at least 87 or 49% of the BSPs), physical restraint (within 32 or 18% of the BSPs), "sharps restrictions" (within 19 or 11% of the BSPs), and behavioral two-to-one aides (within 15 or 8% of the BSPs).
- RCRC reviewed fifteen (15) requests for exemption from the requirement of having a BSP. All of these were approved.

¹ DDS HRAC Procedures, Procedure No. 2013-DDA-H&W-PR012, at Section 3.A.2.b, available at <https://dds.dc.gov/node/738902> (eff. September 3, 2013).

² See *id.* at Section 3.A.3.f.ii.

³ 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."

⁴ 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).

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 past recommendations. For example, RCRC started using a “Yes, with recommendations” designation, when it determined a BSP met one of the eight required criteria in the DDS RCRC Procedure but had further recommendations for improvements that should be made to the BSP.⁵ However, our review this quarter revealed that that RCRC has largely stopped using the “Yes, with recommendations” designation. There were many instances in which RCRC answered “Yes” to the BSP meeting a required criterion, but then noted the need for improvements, justifications, BSP revisions, or additional information of a nature that calls into question whether that criteria was truly met. As an illustrative example:

- In December 2018, RCRC approved one BSP and the restrictive control within it (namely, psychotropic medications) for an almost two-year period. Under DDS Procedure, in order to approve a BSP, RCRC must find that the BSP meets each of the eight criteria for approval, as well as “professional standards.”⁶ RCRC answered “Yes” to eight criteria, indicating that the BSP included: (1) targeted behavior that is consistent with the person’s diagnosis, (2) relevant data collection, (3) demonstrated review of that data by the psychologist, (4) procedures to address behavioral issues consistent with DDA policies, (5) a functional analysis, (6) proactive and positive strategies, (7) a rationale for using the restrictive interventions; and (8) benchmarks for reducing the restrictive interventions. Yet RCRC’s accompanying notes suggested there was problems with relevant data collection (related to criterion 2) because the operational definitions for certain target behavior needed to be revised to be measurable and linked with an unfavorable consequence. They also suggest that the BSP may not comply with DDA policies for addressing behavioral issues (related to criterion 4), in that the psychiatric assessment was expired and that the diagnosis it included did not coincide with what was in the BSP. RCRC also noted there were flaws with the functional assessment (related to criterion 5) upon which the BSP was based, namely that it needed to specify the specific antecedents, consequences, and function in observable behavioral terms. It also found that the person’s medications did not correlate with the person’s diagnoses (related to criteria 4 and 7), e.g., the person is prescribed medications for anxiety and insomnia without those diagnoses. In the end, RCRC required the BSP to be revised accordingly and uploaded into MCIS in 30 days so that RCRC could re-review it – despite RCRC having just approved the unrevised BSP for an almost two-year period.

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

- 49 BSPs (28%) were approved, even if they referred to a restrictive control for which RCRC required further justification.
- 41 BSPs (23%) were approved, even though RCRC required the submission of additional supporting information (e.g., behavioral data, proof of training, medical clearance/evaluation, or second opinions regarding prescribed medications).
- 38 BSPs (21%) 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.⁷
- 6 BSPs (3%) were approved, even if they referred to a restrictive control that RCRC expressly rejected or deferred.

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.

Conclusion

Since the close of the Evans case the District government has:

- Seen the renewal of the Home & Community Based Services Medicaid Waiver (HCBS)
- Developed and implemented new policies and procedures

⁵ See DDS Guidance for RCRC Review of Behavioral Support Plans, available at <https://dds.dc.gov/node/803762>

⁶ DDS RCRC Procedure Section 3(D)(4)(a)

⁷ 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.”

- Received CMS approval for a plan to implement Medicaid's new HCBS settings rule
- Continued to manage its budgetary authority to avoid a formal waiting list for applicants
- Wisely allocated funding provided by the Council to achieve all top priorities
- Maintained stability in the senior leadership of DDA

Each of the above points is a significant achievement and has contributed to the important goal of sustaining the gains made that led to the closure of the litigation. DDS has also continued its efforts at ongoing improvement through various projects that address areas such as supporting families, employment, and person-centered thinking.

Unfortunately, because of the nature of our advocacy work, Quality Trust continues encounters examples where the system does not meet needs, fails to exhibit urgency, lacks flexibility, and/or ignores the preferences and individuality of some the people who are part of the DDS system. It is at these times that people are most likely to call on Quality Trust to help them navigate through the system to get their needs met. During the first quarter, we assisted people and their families whose lives were disrupted by the disconnect between good intentions and best practice aspirations and the reality of day to day practice on the ground level. In certain instances, multiple follow-up conversations with Service Coordinators, supervisors, senior leadership, and occasionally outreach to Councilmembers and Committee staff are required to achieve basic outcomes, such as a move to a new provider, obtaining a new service, or gaining access to DDS or RSA services.

As noted in this report, we remain concerned that:

- Many requests for lay advocacy are made to achieve outcomes which should be easily handled within the day to day tasks of DDS Service Coordinators
- As we have noted in previous reports, we remain concerned that such a high percentage of Serious Reportable Incidents are closed without a finding of responsibility on the part of providers or Service Coordinators
- As cited above, we often find ourselves interacting with some people multiple times for different reasons. Again, many of these supportive actions could and should be accomplished by Service Coordinators
- While past improvements have occurred in the HRAC and RCRC processes, we encourage DDS to revisit those committees' practices to further ensure BSPs and LTAC and nursing home placements are not approved in a way that is contrary to the text and spirit of its own policy and procedure.

While much has been achieved between the closure of the Evans case in January 2017 and today, there remains much for DDS to do if it is to create consistent, high quality supports tailored to the unique needs and preferences of everyone in the DDA system in the District of Columbia. We remain committed to working with DDS to continue their efforts to make the needed improvements in the service system through our monitoring and advocacy activities.