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## **Second Quarter Monitoring Summary**

**January 1, 2019 – March 30, 2019**

### **Introduction**

This is the second quarterly monitoring and lay advocacy report for FY 2019. The report, covering January 1, 2019 to March 30, 2019 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 details Developmental Disabilities Administration and the Department of Disabilities Services (DDA/DDS) requests for lay advocacy, along with our follow up on Serious Reportable Incidents (SRI's), and our work ensuring placements to Long Term Acute Care Facilities (LTACS) were proper and that people placed returned home to safe and supportive service arrangements. We track and trend SRI's and assess the quality of investigations into those incidents. DDA sends us the minutes of DDS/DDA's Restrictive Rights & Control Committee (RCRC) and the Human Rights Committee meetings which we analyze for trends and quality. Through our participation in the (MRC), Mortality Review Committee, we review investigations of deaths completed by an independent entity; the Columbus Organization. We have concerns about those investigations and have included a section on them in this report. As we do every year, we testified at both performance and budget hearings for FY 2019 and 2020 for DDS.

We continue our monitoring project focused on Unplanned Emergency Inpatient Hospitalizations (UEIH). The focus of the analysis are the antecedents, outcomes, follow up, and investigation of a statistically significant random sample of incidents. Unplanned hospitalizations are the most numerous category of Serious Reportable Incident. These visits regularly account for approximately forty (40%) of all incidents. The causes for these visits are varied, but some recurring causes are: UTI, constipation/bowel issues, dehydration, fever, seizures or complications from seizures and issues surrounding Gtube placement. Typically, these diagnoses are made after the provider staff notices that the person is displaying symptoms of concern such as excessive fatigue, fever, lack of appetite or in ability to sleep through the night. Investigations of these incidents are completed by the provider. Once completed, the investigation is submitted to the Investigation Management & Enforcement Unit (IMEU) of DDSS/DDA. The IMEU investigator reviews the provider investigation to ensure it meets standards set forth in policy. At the core of any investigation is answering the investigatory question. In these investigations that is: did abuse or neglect cause the person to go to the hospital in an unplanned manner. The final classifications for all investigations are: substantiated, unsubstantiated, resolved-no abuse or neglect found, inconclusive, administrative closure, and two sub classifications: substantiated for abuse and substantiated for neglect. These final classifications are often used when evidence in an investigation leads to findings for an alternative incident type. For example, if an investigation for serious physical injury leads to a substantiation for abuse, the incident is then reclassified as abuse.

In only two percent (2%) of incidents was the above question answered in the affirmative as reflected in the chart included with this report. In fact, 84 of the 90 UEIH's closed this quarter (93%), were classified as resolved-no abuse or neglect found. This is a different classification than unsubstantiated. Had 93% of such incidents been unsubstantiated, a clear and unambiguous inference could be drawn that the provider's nursing supports did not cause the hospitalization. The classification of Resolved-No Abuse or Neglect Found leaves an open question about causation. If there were questions about supports provided to the person, the outcome should be substantiated. If there were not, there should be no substantiation. When Resolved-No Abuse or Neglect found is used there is a distinction without a difference. The question then becomes. What purpose does this classification serve? We have urged DDS to address this issue as it reviews and updates the IMEU policy and procedure.

The following data are the results from our work for the second quarter.

**Advocacy**

New referrals for advocacy: 19

Outcomes Met or Closed: 15

Sources of advocacy referrals

QT	DDS SC	Family	Outside agencies
1	4	11	3 AARP, Legal Counsel for the Elderly and Successful Parenting of DC

**Requested outcomes for new referrals**

DDA application support	5
New benefits or loss of benefits	3
In home help	1
Healthcare follow up	4
RSA concerns	1
School concerns	1
Environmental needs	1
Residential change	1
DDS appeal	1
New bed needed	1

**Outcomes met this quarter: 15**

<b>Number of Outcomes Met</b>	<b>Outcome</b>
3	Residential move/residential issues resolved
4	RSA/day program or employment in place
1	New bed received
1	Medical recommendations completed
2	DDS application submitted
1	DAR completed
1	In home staff put in place
1	Respite in place
1	Improved communication/issues resolution between family and provider

**LTAC Follow UP**

**Number of LTAC follow Up Visits: 7**

- We received notification from DDS of seven (7) people going into LTAC placements
- There were no concerns regarding appropriateness of setting at the time of placement
- Three (3) people returned to their homes. One (1) person was placed in an ICF. One (1) person went from a natural home to a Supported Living placement. One (1) person went to a level two placement due to a decline and One (1) person is currently placed in an LTAC facility
- Two (2) people required additional follow-up from QT nursing

<b>Reason for LTAC (note that people have multiple reasons)</b>	<b>Number of people</b>
Antibiotic Therapy	1
OT/ PT	3
Weaning off Tracheostomy	2
Accident/S.P.I. follow up	1
Requirement for Skilled Nursing	1

### **Serious Reportable Incident Follow Up**

**Total SRI follow-up: 14 assigned**

<b>Incident Type</b>	<b>Number</b>
UEIH	5
Neglect	2
Abuse	1
SPI	5

#### **Follow-up Post Unplanned Emergency Inpatient Hospitalizations:**

- 5/5 (100%) people had recommendations made at the time of discharge
- 5/5 (100%) people hospitalized reported feeling better
- 2/4 (40%) people needed continued advocacy. One person received a new g-tube and our nurse followed up to verify it was working, and that staff were trained on its proper use. The other person's family asked that the QT nurse continue to follow the person to ensure proper that care was in place post discharge
- No new SRIs were generated after these visits

#### **Non-medical follow up:**

- All people were deemed to be safe after the visit
- One (1) person had 2:1 staffing put into place in the aftermath of the incident
- Two providers (2/2) removed staff after abuse incidents
- No new SRIs were generated after these visits as well

#### **Deaths**

- Nine (9) deaths occurred this quarter
- One (1) death occurred in a nursing home
- Three (3) deaths involved people supported by the same provider; two occurred within one week and involved residents of the same home
- Two deaths involved behavioral health issues; one involving circumstances surrounding One (1) person dying during the employment of an unapproved restraint and the other choking while experiencing a behavioral health incident
- The average age at time of death was 58, and the mean 50
- The ages of the people who died were (23, 41, 47, 53, 61, 67, 71, 72 & 83)

**Serious Report Serious Reportable Incidents & Investigations Q 2**

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect)	Percent substantiated	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)					Percent not substantiated			
				1	3	3	14	49	12%	11%	5%	Total = 78%
337	273 (81%)	51 + 10 = 61	22%	1 3 5	3 2	3 1		%				

**Breakdown of Serious Reportable Incidents Q2**

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
<b>UEIH</b>	90	33%	2% (2 of 90)	98% (88 of 90)
<b>Neglect</b>	72	26%	54% (39 of 72)	46% (33 of 72)
<b>Serious Physical Injury</b>	57	21%	11% (6 of 57)	89% (51 of 57)
<b>Abuse</b>	33	12%	30% (10 of 33)	70% (23 of 33)
<b>Missing Person</b>	6	2%	17% (1 of 6%)	83% (5 of 6)
<b>Exploitation</b>	12	4%	25% (3 of 12)	75% (9 of 12)
<b>Serious Medication Error</b>	1	<1%	0% (0 of 8)	100% (1 of 1)
<b>Inappropriate use of restraints causing injury</b>	3	1%	67% (2 of 3)	33% (1 of 3)
<b>Suicide Attempt</b>	1	<1%	0% (0 of 1)	100% (1 of 1)
<b>Death</b>	9	3%	N/A	N/A

**Serious Reportable Incidents & Investigations Q1**

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 Q1**

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

## **SRI Data Analysis**

- Overall incidents were down slightly, but the number closed was nearly identical
- The percentage of overall substantiation of incidents was again remarkably low (21%), Q1, (22%) this quarter
- As noted in the introduction, the level of substantiation for UEIH's was also consistently low (1%), Q1, (2%) Q2.
- Levels of substantiation for Neglect, Abuse & Serious Physical Injury were significantly statistically higher than UEIH's. This is a typical pattern. The cause for these findings is unclear
- Neglect, as it always has been is the most substantiated Serious Reportable Incident
- There was only one death in the first quarter, while there were nine this quarter,
- Although that is a significant spike, the trending with the current numbers would result in twenty deaths, lower than a typical year

## **HRAC & RCRC Review:**

### **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. During the first quarter of fiscal year 2019 DDS provided Quality Trust with the minutes from HRAC meetings held on January 23, 2019, February 27, 2019, and March 27, 2019.

Based on the minutes provided, the HRAC reviewed 36 human rights issues for 27 people during this quarter.

- 16 issues (44%) were about Long Term Acute Care ("LTAC") placements.
- 5 issues (14%) were about out-of-state residential placements
- 4 issues (11%) were about nursing home placements.
- 5 issues (14%) were about restrictions, including those relating to BSP exemption; psychotropic medication titration; a lock outside of a bedroom door; prohibition on use of alcohol, drugs, and tobacco; and limitations on a person's right to time alone with his or her significant other.
- 6 issues (17%) were about other human rights concerns, including requests to be supported by particular staff, refusals to go to medical appointments or provide medical documentation to providers; and refusal to contribute to the cost of residential supports.

In our prior reports, we recommended HRAC engage in more thorough review of out-of-state placements to determine if they really are the least restrictive and most appropriate settings to meet the needs of the people who live in them. Therefore, we appreciate that the HRAC minutes this quarter reflect a more robust committee discussion when such placements were reviewed. For example, this quarter, HRAC reviewed placements of five residents at Crystal Springs, an out-of-state rehabilitation habilitation provider, and identified issues relating to quality of health care, the need for more individualized employment and day programming plans, and the need to explore whether the person was satisfied with the placement or wanted to move back to the DC area near family. However, in all five cases, HRAC still approved the out-of-state placement, even when it had identified concerns to be addressed by the provider and/or DDA. In such cases, it would be more consistent with DDS Procedure for HRAC to defer its determination until it receives an update on the actions taken in response to its concerns.

### **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 ("BSP's) of people served by DDA to ensure restrictive controls within them are appropriately justified. These minutes are generally provided by DDS on a monthly basis.

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

- RCRC reviewed a total of 171 BSPs for 151 people.
  - All the reviews appeared to be non-emergency reviews of new BSPs (131; 77%) and updated BSPs (40; 23%).
- Of the BSPs reviewed, the vast majority were approved (158; 92%) were approved. A subset of these BSPs were approved for 30 days only (2 BSPs), 60 days only (4 BSPs), 90 days only (9 BSPs), and 6 months only (1 BSP).
  - 87 (51%) of the BSPs reviewed 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.<sup>1</sup>
  - 12 (7%) of the BSPs reviewed were approved without clear RCRC answers to one or more of the 8 criteria being included in the minutes.
  - 1 of the BSPs reviewed was approved, even though RCRC indicated that one of the required criteria was not met.
  - 2 (1%) of the BSPs were rejected.
  - 10 (6%) of the BSPs were deferred.
  - 9 (5%) of the BSPs were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 required criteria.<sup>2</sup> More specifically, RCRC found:
    - In at least 5 of these cases, the BSP did not include a rationale for using the restrictive interventions
    - In at least 3 of these cases, the BSP did not include proactive and positive strategies
    - In at least 2 of these cases, the BSP did not include targeted behaviors that were consistent with the person's diagnoses.
    - In at least 2 of these cases, the BSP did not include relevant data collection.
    - In at least 2 of these cases, the BSP did not include procedures to address behavioral issues consistent with DDA policies.
    - In at least 2 of these cases, the BSP did not include benchmarks for reducing restrictive interventions.
    - In at least 1 of these cases, the BSP did not include a functional analysis.
    - The three most common restrictive controls reviewed were the use of psychotropic medications (within at least 154 or 90% of the BSPs), behavioral one-to-one aides (within at least 73 or 43% of the BSPs), and physical restraint (within at least 34 or 20% of the BSPs).
    - RCRC reviewed 7 requests for exemption from the requirement of having a BSP. 6 of these requests were approved, and 1 was rejected.

As noted in our prior reports, we had seen improvements made to the RCRC processes, as reflected in its minutes and in response to our past recommendations. Unfortunately, this quarter, we saw several instances where certain fields within the minutes template were either left blank or were unclear. We encourage DDS to ensure the RCRC minutes going forward are consistently thorough and complete.

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

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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).



- At least 62 BSPs (36%) were approved, even if they referred to a restrictive control for which RCRC required further justification.
- At least 46 BSPs (27%) 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>
- At least 9 BSPs (5%) were approved, even though 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

During the first two quarters of the Fiscal Year our work advocating for people with intellectual and other developmental disabilities and their families and our data indicate that the District government has:

- Continued to reform the methods by which services and supports are provided in the District
- Continued to work internally to reform the methods by which DDS/DDA does its work
- Continued to revise policies and procedures

Requests for our advocacy support continues to center on what are typically characterized as case management functions. We encounter situations where people with disabilities and/or their families are unhappy with the choices they are offered, and the process used to meet their needs. Most often lack of urgency by provider staff or DDA Service Coordinators compels people to reach out to Quality Trust. As we noted in our first quarter report, repeated interventions are typically required to achieve successful outcomes of basic requests such as replacing or obtaining a piece of adaptive equipment, ensuring that the person's preferences are adequately considered during provider selection, choice of home, etc.

As noted in this report, we continue to advocate for changes to the IMEU policy and hope that strong consideration be given to elevating UEIH's to level one status, and/or that nurses review provider investigations of these incidents.

Also as noted in our performance testimony in February, the closure of Providence Hospital, and the decision to close United Medical Center will reduce the number of hospitals available in areas of the city where many people with disabilities reside. We await a formal plan to address these closures.

Finally, as we noted in both our testimony's this year, current funding for IDD services in the District only maintains the status quo, but we know that the needs of former residents of Forest Haven in their later years and a large influx of people with Autism are bound to increase costs significantly. It is important that planning for these realities begin sooner rather than later. We look to DDS to take the lead in preparing The DC City Council and greater stakeholder community for the work ahead in these areas.

The District's IDD system is small enough that delivering high quality supports tailored to the unique needs and preferences of each person is achievable. We remain committed to fulfilling our role through our monitoring and lay and legal advocacy and striving to achieve the goal of quality services for everyone.

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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."