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Fourth Quarter & Final Fiscal Year 2019 Monitoring Summary

June 1, 2019 – September 30, 2019

Introduction

This is the fourth quarterly monitoring and lay advocacy report for FY 2019. This report covers the period of June 1, 2019 to September 30, 2019 as well as cumulative data from our work during the past year. The report 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.

In this the final quarter of FY 2019, the DD system in the District of Columbia is approaching almost three full years removed from the *Evans* litigation. Whatever one believes about the efficacy of that lawsuit; (whether reforms went far enough, or too far to bring about lasting systemic change) new patterns and realities are beginning to emerge. DDS has undertaken extensive changes in policy and procedure since 2017. Some of these changes were initiated voluntarily by the leadership, while others were driven by mandates put on all states by the Center for Medicaid and Medicare Services (CMS). Stakeholders have been concerned by some of the changes to the availability and cost of services. Many were taken by surprise when DDS leadership decided not to continue the DDS Health Initiative implemented through a contract with the DC University Center on Excellence in Developmental Disabilities (UCEDD) at Georgetown. Quality Trust expressed our concern in multiple venues in real time about that decision. More concerning though was the lack of stakeholder engagement around the plan to transition these services to another provider and to staff internal to DDS. DDS leadership did reach out to the stakeholder community this fall to reengage in dialog about a host of issues facing people with IDD and their families. A loosely affiliated stakeholder group organized during the uproar brought about by the Georgetown contract being discontinued has remained is now working to build consensus around a broader array of issues that will guide the direction of services in the future. A sustained presence of non-government stakeholders is necessary and important currently in the development of the post litigation system. Improved communication coupled with a greater sense of partnership between DDS, providers and people with disabilities is an area for improvement in the coming year. DDS launched two separate initiatives this Fiscal Year involving stakeholders in discussions about policy, practice and the near-and longer-term direction of services and supports in the District. These processes have not yet produced tangible results but could be important steps in developing the trust that was lost around the roll out of some of the system change efforts launched over this fiscal year. We in the advocacy community will be hopeful for transparent, meaningful collaboration as we engage with DDS moving forward.

This report is a summary of the many and varied activities in which we have engaged or participated as part of our ongoing advocacy and monitoring. These activities are centered on the outcome of elevating the effectiveness and responsiveness of services and supports for people using DDA services and supports. The provision of healthcare to the 2394 people comprising the DD system in the District still has many weak points as is demonstrated by the data discussed and analyzed here related to our follow up on Serious Reportable Incidents (SRI's), and our work ensuring placements to Long Term Acute Care Facilities (LTAC). This report also includes information about the observed quality of nursing services

across congregate living models, and from direct participation in the (MRC), Mortality Review Committee. The MRC committee reviews investigations of deaths completed by an independent entity; the Columbus Organization. We have identified concerns about those investigations that have been shared with DDS through the MRC review process. We also receive DDA minutes of DDS/DDA's Restrictive Rights & Control Committee (RCRC) and the Human Rights Committee meetings which we analyze for trends and quality.

Our monitoring project for this fiscal year focused on Unplanned Inpatient Emergency Hospitalizations (UEIH). We found that statistically speaking, the current system is properly investigating these incidents, though we remain in fundamental disagreement with how their dispositions are categorized. Based on the information presented we could not dispute the classification of most incidents as not connected to abuse or neglect on the part of the provider nursing staff or primary care physicians. That said, we did uncover a few very disturbing situations which are discussed in this report. Unplanned hospitalizations are the most frequently occurring incident category of all incident types. Significantly, nearly all these incidents (close to 100%) are closed with no abuse or neglect found to have caused the unplanned visit. More broadly, across all categories, the level of substantiation for abuse or neglect is typically low. In fact, as the charts in this report demonstrate, except for neglect and exploitation substantiation is rarely higher than approximately 20%. There is no generally expected level of substantiation, however, given our concerns regarding weaknesses in health care supports and the fact that after investigation, almost eight of ten incidents are not linked to any failures on the part of those supporting people receiving services, we recommend that DDS focus significant time and effort examining this aspect of incident management more deeply.

The following basic demographic data of the people supported by DDS are presented to create context for the results contained in this report.

The five biggest residential settings continue to be:

- Natural Home: **954**
- Supported Living: **941**
- Intermediate Facility: **311**
- Residential Habilitation: **119**
- Host Home: **88**

Waiver	1830
ICF	303
Non ICF and Non Waiver	270

Advocacy

Active advocacy: 30

Outcomes met/closed: 12

# of outcomes met	Outcome
2	Moved

1	Visitation schedule arranged between family and provider
1	Closed due to inability to receive services (family cannot account for \$40,000. Not eligible for Medicaid)
3	Environment issues resolved
1	Wounds healing
2	Person died
1	Person went home from LTAC
1	Medicaid reinstated and all services started again.

Sources of advocacy referrals

Provider	Outside agency	QT Internal referrals	Family	DDS	Person receiving services	Public Defender
1	1	1	5	4	1	1

Requested outcomes from new referrals

DDA application support	2
Psychiatric support post sexual assault	1
Residential change	1
DDS appeal	1
In jail/future planning	1
End of life planning	1
Third party mediation	2
BSP problems	1
Visitation issues	1
Access to services	1

Natural home/neglect issues	2
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LTAC Follow UP

Number of LTAC follow Up Visits: 5

- We received notification from DDS of five (5) LTAC placements during this quarter. One (1) of this group did not go to LTAC but went directly back to her home instead.
- There were no concerns regarding appropriateness of setting at the time of placement

Reason for LTAC (note that people have multiple reasons)	Number of people
Antibiotic Therapy	3
OT/ PT	2

Serious Reportable Incident Follow Up

Total SRI follow-up: 13 assigned, although 1 person died the day after the assignment and was never seen.

Incident Type	Number
UEIH	9
Serious Physical Injuries	2

Abuse	1
Neglect	1

Follow-up Post Unplanned Emergency Inpatient Hospitalizations:

- 9/9 (100%) of people went back to their homes.
- 9/9 (100%) people had recommendations made at the time of discharge
 - 4/9 (31%) had met their recommendations at the time of the visit
- 5/9 (56%) had recommended appointments scheduled at the time of the visit
 - 9/9(100%) people hospitalized reported feeling better
 - 1/9 (11%) person needed continued advocacy for medical follow up.
 - No new SRIs were generated after these visits

Non-medical follow up:

- All people were deemed to be safe after the visit, except one (1) person who was referred for advocacy
 - No new SRIs were generated after these visits
- Responses for increased safety included staff removal, staff training, police intervention, team meetings and doctors' visits.

Deaths

- Eight (8) deaths occurred this quarter
 - One (1) person was living in a nursing home at the time of her death.
- The ages of the people who died ranged from 55 – 73 (55,47,55,68,63,66,68 and 73).
 - The average age at the time of death was 62
- Causes of death were listed on SRI's as cancer x 2, possible cardiac arrest x 3, 2 people in hospice, sepsis.

Advocacy Totals for FY 2019

New referrals	Outcomes achieved/closed
57	54

Advocacy Outcomes achieved or closed in FY 2019

Moved	Day issues resolved	Added new waiver services	Environment issues	DDA application support	DDA application appeal	Communication issues resolved	New guardian appointed	Medical issues resolved	Future planning
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11	4	5	4	3	2	3	1	12	3
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Psychiatric supports put in place	BSP issues	Natural home/neglect issues	Benefits reinstated	School transition	Spanish speaking support	People who died or asked to close
1	1	2	1	1	1	3

Fiscal year 2019 continued to show a consistent number of referrals. In fy 2018 there were 57 new referrals, as well as 57 in fy 2019. 33 outcomes were met, and 6 people did not continue with advocacy, either due to their own choice or death. Outcomes met were increased in fy 2019 from fy 2018 by 37%.

LTAC FY 2019

- Twenty-six (26) total LTAC visits were made
- One (1) person never went to LTAC after receiving notification and went straight home
- The most recommended services/care was antibiotic therapy, physical therapy, vent and trach weaning and general rehabilitation.
- There were no concerns that anyone should be placed in a lesser restrictive environment.

SRI follow-up FY 2019

- There were fifty-two (52) serious reportable follow up visits completed in FY 2019
- Once again, UEIH was the largest category of assigned follow up.
- 100% of people who were hospitalized had recommendations made at the time of discharge
- No new SRIs were generated after our initial visits.
- Eight (8) people were referred internally for advocacy after the initial visit.
- Responses to neglect and abuse were staff training and staff removal.
- All people were deemed free from harm after initial visits.

UEIH	Neglect	Abuse	SPI	Exploitation
28	12	4	7	1

A STORY FROM OUR FOLLOW UP

During FY 2019 Quality Trust was contacted by a Service Coordinator from DDS who requested advocacy support for a person she supported. It was reported that the person had cancer which had metastasized. The Service Coordinator indicated that she feared the provider had been neglectful of the person's medical and nursing needs. An advocate and nurse visited the person; reviewing his records and interviewing him and his staff. During the interview the person was asked how he was feeling and what his thoughts were about his diagnosis. He expressed that he was feeling better; but that he had been sick and lost a lot of weight.

After reviewing the documentation and completing the interview it became clear that routine yearly testing which could have avoided the serious health situation now experienced by the person had been neglected. The failures were pervasive: from his primary care physician, to the specialist, to the provider nursing staff, and ultimately from the Service Coordinator herself even though it was she who made the referral. It was also clear that the failures had occurred repeatedly over several years. Initially the person received tests results indicating an elevated marker for possible cancer. Prudent and sustained follow up should have occurred. Instead of carrying out routine and commonly available testing his specialist, primary care physician, provider nurse and QIDP and his DDS Service Coordinator all failed to ensure that testing and early intervention were made available. Despite several years of bloodwork presenting elevated levels of concern which continued to climb, no one intervened. As a result, the cancer spread throughout his body. Sadly, the type of cancer he developed is very easily treated when caught early.

Given the seriousness of his situation Quality Trust referred him to outside counsel who agreed to represent him to arrive at a settlement. The situation is currently in litigation.

This situation not only demonstrates how important health monitoring and medical follow-up is for people, but also the degree to which communication and continuity of care are paramount in protecting the health and wellbeing of people receiving supports and services through the DDS system.

Serious Report Serious Reportable Incidents & Investigations FY 2019

Total Incidents	Number closed	Number Substantiated (substantiated & substantiated for neglect and/or abuse)	Total	Total %	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)				Total	Total %				
1227	1190 (97%)	194+54+3	251	21%	601	125	113	79	1169	51%	11 %	9%	7%	Total= 79%

Breakdown of Serious Reportable Incidents FY 2019

N =1190 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	429	36%	2% (10 of 429) • 5 substantiated for neglect	98% (399 of 429) • 399 (93%) resolved-No abuse or neglect found
Neglect	269	23%	53% (142 of 269)	47% (36 of 269)

Serious Physical Injury	199	17%	14% (25 of 199)	86% (172 of 199)
				<ul style="list-style-type: none"> 149 of 199 resolved-No abuse or neglect found
Abuse	138	12%	28% (39 of 138)	72% (99 of 138)
Exploitation	57	5%	82% (47 of 57)	18% (10 of 57)
Missing Person	43	4%	14% (6 of 43)	86% (36 of 43)
				<ul style="list-style-type: none"> 1 upgraded to allegation of abuse, neglect or exploitation
Serious Medication Error	20	2%	10% (2 of 20)	90% (18 of 20)
Other	8	>1%	12% (1 of 8)	82% (7 of 8)
Death	35	N/A	N/A	N/A

Serious Report Serious Reportable Incidents & Investigations Q 4

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect and/or abuse)	Total	Total %	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)				Total	Total %				
395	340 (86%)		50 + 23 = 73	21%	167	35	34	29	265	49%	10 %	10%	8%	Total= 79%

Breakdown of Serious Reportable Incidents Q4

N =340 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	128	38%	4% (5 of 128)	96% (123 of 128)
			<ul style="list-style-type: none"> 5 substantiated for neglect 	<ul style="list-style-type: none"> 117 (91%) resolved-No abuse or neglect found
Neglect	77	23%	53% (41 of 77)	47% (36 of 77)

Serious Physical Injury	54	16%	22% (12 of 54)	78% (42 of 54) <ul style="list-style-type: none"> 34 of 54 resolved-No abuse or neglect found
Abuse	41	12%	20% (8 of 41)	80% (33 of 41)
Exploitation	18	6%	78% (7 of 9)	23% (2 of 9) <ul style="list-style-type: none"> 1 unsubstantiated & 1 administrative closure
Missing Person	14	4%	14% (2 of 14)	86% (12 of 14) <ul style="list-style-type: none"> 1 upgraded to allegation of abuse, neglect or exploitation
Serious Medication Error	6	2%	17% (1 of 6)	83% (5 of 6)
Other	2	>1%	0% (0 of 2)	100 (2 of 2)
Death	13	N/A	N/A	N/A

Serious Report Serious Reportable Incidents & Investigations Q 3

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect and/or abuse)	%	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)				%				
289	151 (52%)	26 (17%) + 7 (5%) = 33	21%	82	16	10	10	54%	11%	7%	7%	Total= 79%

Breakdown of Serious Reportable Incidents Q3

N =151 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	50	33%	4% (2 of 50) <ul style="list-style-type: none"> 1 substantiated for neglect & 1 administrative closure 	96% (48 of 50) <ul style="list-style-type: none"> 48 resolved-No abuse or neglect found

Serious Physical Injury	34	22%	9% (3 of 34)	91% (31 of 34) <ul style="list-style-type: none"> 28 of 31 resolved-No abuse or neglect found
Neglect	27	18%	48% (13 of 27)	52% (14 of 27)
Abuse	19	13%	37% (7 of 19)	63% (12 of 19)
Exploitation	9	6%	78% (7 of 9)	23% (2 of 9) <ul style="list-style-type: none"> 1 unsubstantiated & 1 administrative closure
Missing Person	7	3%	17% (1 of 4)	83% (5 of 6)
Serious Medication Error	3	1%	0% (0 of 2)	100% (1 of 1)
Use of unapproved restraints	1	<1	100% (1 of 1)	0% (0 of 1)
Other	1	<1	0% (0 of 1)	100% (1 of 1) <ul style="list-style-type: none"> Administrative closure
Death	12	8%	N/A	N/A

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			
				13	32	31	14	49	12%	11%	5%	Total=
337	273 (81%)	51 + 10 = 61	22%	5				%				78%

Breakdown of Serious Reportable Incidents Q2

N= 273

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	90	33%	2% (2 of 90)	98% (88 of 90)
Neglect	72	26%	54% (39 of 72)	46% (33 of 72)

Serious Physical Injury	57	21%	11% (6 of 57)	89% (51 of 57)
Abuse	33	12%	30% (10 of 33)	70% (23 of 33)
Missing Person	6	2%	17% (1 of 6%)	83% (5 of 6)
Exploitation	12	4%	25% (3 of 12)	75% (9 of 12)
Serious Medication Error	1	<1%	0% (0 of 8)	100% (1 of 1)
Inappropriate use of restraints causing injury	3	1%	67% (2 of 3)	33% (1 of 3)
Suicide Attempt	1	<1%	0% (0 of 1)	100% (1 of 1)
Death	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

N= 274

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

- Overall incidents were down slightly, but the number closed was significantly lower. This is not a concern with the pace of closure on the part of IMEU, rather it is a function of the timing of this report.
- Overall the percentage of substantiation of all incidents was again remarkably low (21%),
- As noted in the introduction, the level of substantiation for UEIH's was also consistently low (2%),
- Levels of substantiation for Neglect & Exploitation (53% & 78%) were significantly statistically higher than UEIH's. This is a typical pattern. The cause for this finding is unclear
- There were 35 deaths over the Fiscal Year which is well within the norm over the past several years
- DDS is currently undertaking a rewrite of the definitions, policies and practices with the IMEU. Quality Trust has provided our insights and recommendations on that process guided by these results, and those of our Triage and SRI follow up visits.

Results from our analysis of UEIH's

As noted earlier, we have concluded our analysis of unplanned hospitalizations. Our methodology employed a tool that looked at relevant issues leading up to the hospitalization, e.g. review of any nursing notes, prior hospitalizations and ER visits that didn't lead to a hospitalization, the discharge documentation from the hospitalization and the investigation of the incident, both by the provider and, when applicable IMEU. The questions we were seeking to answer were: Were any signs or symptoms missed that lead to the unplanned trip to the emergency room? What diagnosis was made at the hospital? Were discharge recommendations followed? Did they address health issues satisfactorily? What issues were brought out in the investigation? Was the final disposition, e.g. substantiated or unsubstantiated for abuse or neglect as a cause of the unplanned hospitalization? Here are some highlights of our conclusions:

1. 98% of the hospitalizations reviewed had a final disposition of: resolved-no abuse or neglect found.
 - a. DDS considers this disposition evidence that the unplanned hospitalization was not the result of abuse or neglect regarding the nursing and healthcare services provided to the person. As we have pointed out previously, this classification would seem to duplicate the classification of unsubstantiated, which already exists. Specifically, substantiated or unsubstantiated is connected to level one incidents, e.g. those incidents which IMEU investigates. UEIH's are level two investigations, those investigation categories providers are permitted to take the lead on investigating. DDS leadership notes that due to the great number of UEIH's, it is necessary to classify these incidents as level two thereby freeing up IMEU investigators to concentrate on alleged abuse, neglect and exploitation. We have disagreed with this policy direction and requested changing UEIH's to level one or adding nurses from Health & Wellness to oversee these investigations. DDS is currently updating the Incident Management & Enforcement Unit policies and procedures.

There are no plans to change the current reality concerning this type of incident definition or disposition.

2. Per the Serious Reportable Incidents, symptoms which lead to most of the trips to the ER were physical manifestations of illness such as:
 - a. Pain expressed by moaning
 - b. Lethargy/fatigue/drowsiness
 - c. Nausea/vomiting
 - d. Sweating, distended abdomen
 - e. Unsteady gait
3. The most typical initial diagnoses were:
 - a. Pneumonia
 - b. Dehydration
 - c. Sepsis
 - d. UTI/Kidney issues
4. Fifty-nine (59%) of the hospitalizations lasted from 2-7 days
5. Another thirty (30%) lasted more than one to two weeks.
 - a. We did not capture the reasons for the longer hospitalizations, but that is an area that Health & Wellness and QA/QI might want to review as the longer one is in the hospital the greater the risk of infection and other negative health outcomes
6. Seventy (70%) of those reviewed had not experienced a hospital admission, and seventy-three (73%) an ER visit in the three months prior to, or after the one we reviewed.
 - a. That three quarters of the sample were single rather than repeat admissions is significant.
7. Ninety (90%) of Service Coordinators had completed required monitoring tools concurrent to the admission, but only sixty (60%) addressed the issues present in the hospitalization
 - a. The value of monitoring tools is diminished when they do not uncover and or follow up on relevant issues in real time
8. Seventy-seven (77%) of the people we reviewed experienced symptoms for 24 hours or less prior to admission
 - a. When combined with the findings in bullet 2, DDS Health & Wellness may want to consider training on signs and symptoms in order to more primitively recognize and address issues before an unplanned hospitalization is required
9. A significant number of provider investigations were accepted by IMEU without requests for more information or significant modification
This finding along with bullets ten and eleven seem to indicate that most unplanned hospitalizations will only be preventable with greater early recognition of and intervention for signs and symptoms of more significant illness
10. We only found a small number of instances where information relevant to the hospitalization was not included in the provider's investigation
11. In a clear number of investigations reviewed our analysis corroborates the provider/IMEU investigation

One of the people in our random sample died after the hospitalization we reviewed. In their investigation of his death, Columbus states, "However, it is unknown if his death might have been prevented on November 25, 2017, had he been sent to the hospital sooner for evaluation, treatment, and monitoring." During our review of the hospitalization prior to his death we found questionable clinical judgments and instances where appropriate follow up was missed:

- The person experienced GI issues which significantly worsened without appropriate follow-up. Three hospitalizations occurred in one month; the final involving severe colon distension, clostridium difficile, possible megacolon, (enlarged colon), acute colitis with gastrointestinal bleed, and hematochezia (bleeding of the rectum).
 - Intervention with the GI doctor would have been a prudent intervention

- Although found to be dehydrated on several occasions, no evidence of fluid monitoring was discovered
- The PCP documented episodes of “delirium”, describing the episodes as “seizure like” symptoms. The HMCP noted the person had a diagnosed seizure condition. The Physician’s order sheet nor the last medical evaluation listed seizures as a diagnosis.
 - A neurology follow-up should have been completed but was not. This was missed by the PCP and the provider nursing staff.
- After he was diagnosed with Cardiomyopathy, He was not prescribed medications to treat this diagnosis.
- Upon discharged from Washington Hospital Center, a follow-up surgical consult was recommended.
 - This did not take place, nor was it addressed in any documentation we reviewed.

In another review made during the study of Unplanned Emergency Hospitalizations it appeared that a crucial part of the discharge information was missed. The omission could have led to the person’s death. In that case, the Columbus investigation notes, “Although the death certificate listed the decedent’s cause of death as sepsis and noted cerebral palsy as a contributing factor, a comprehensive review of the medical records leads this physician reviewer to the conclusion that his death was the result of complications of his J-tube.” Our review revealed the following issues of concern:

- The person was a relatively healthy 46-year-old who had a J-tube due to significant contractures. He had three hospitalizations and one ER visit in the year prior to his death due to G-tube issues (clogging, coming out). He was hospitalized on May 17, 2018, during which his J-tube replaced. J-tube leakage was observed the same day he was discharged home from hospital. The provider nurse contacted the GI surgeon who reportedly stated that he was on vacation and intended to repair the tube upon his return.
- We located a note in the discharge paperwork that was missed at that discharge which stated the following. “J-tube used to administer medications which led to clogging of tube. Feeds started through gastrostomy port and well tolerated. During attempt to declog J-tube line the channel burst, this was repaired with tegaderm and precludes use of J-port. can D/C NG. Advance tube feeds as tolerated via gastrostomy port. Will plan for elective exchange of Jejunostomy on an outpatient basis. Please have patient follow up in clinic in 2 weeks time.”

Our review of the documentation from the Physician and nursing notes reveal that he continued to receive his feedings via his J-tube even though use of the J-port use was precluded due the channel bursting. The discharge paperwork noted that “Feeds should be given through Gastrostomy port until the J-port is replaced on an outpatient basis.” This was not noted in the investigation in the Columbus investigation. We supplied the information to the Mortality Review Committee so that the Columbus investigation could be amended including this information. As noted above, the Medical Examiner noted the cause of death as Sepsis, a condition which could have resulted from continued use of the J-tube.”

As stated earlier, while we concur with the findings of the provider investigations of most of the UEIHs, these examples along with the one provided in the SRI follow up section demonstrate how failures at the provider and clinician level can sometimes result in devastating outcomes.

Conclusions

Unplanned hospitalizations are and have always been the most frequent category of Serious Reportable Incident, accounting for anywhere between 35-38% of all SRI's every year. While our findings suggest that, using the current definitions and dispositions most unplanned hospitalizations could not have been prevented, every effort should be made to identify the person's symptoms earlier and the visit took place at the physician's office, or even an urgent care facility. Accessing healthcare through the emergency room is not only costly, it can also cause unnecessary heightened anxiety to both the person and provider staff. In addition, with the closure of two hospitals that were heavily used by people living in the community in the District using the emergency room will become more problematic in the future. It is therefore recommended that DDS, Health & Wellness unit along with the Quality Assurance and Quality Improvement units undertake a joint project to provide training that places heightened emphasis on identification of and intervention for signs and symptoms of illness in people receiving services and supports in DC.

HRAC & RCRC Review:

HRAC Review Q 1:

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 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 Q 1:

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.

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.

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,

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).

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

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 were 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.

HRAC Review Q 2:

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.

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.”

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 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 Q 2:

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.⁸
 - 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.

⁸ 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.”

- 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.⁹ 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:

- 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.¹⁰
- 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.

HRAC Review Q 3:

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 third quarter of fiscal year 2019 DDS provided Quality Trust with the minutes from HRAC meetings held on April 24, 2019, May 22, 2019, and June 26, 2019. Quality Trust did not receive the approved June 29, 2019 HRAC meeting minutes until August 27, 2019.

⁹ 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).

¹⁰ 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.”

Based on the minutes provided, the HRAC reviewed 44 human rights issues for 26 people during this quarter.

- 29 issues (66%) were about Long-Term Acute Care (“LTAC”) placements
- 8 issues (18%) were about out-of-state residential placements
- 4 issues (9%) were about nursing home placements
- 3 issues (7%) were about other human rights concerns, including those relating to BSP exemption and refusals to go to medical appointments or provide medical documentation to providers.

This quarter, the HRAC rejected placements for not being the least restrictive setting to meet the person’s needs on 6 occasions, and it deferred deciding on six occasions because of the need for more information related to the placement. However, in nine occasions this quarter, the HRAC approved a placement without expressly recording within its minutes that it had found the placement to be “the least restrictive and most appropriate settings to meet [the person’s] needs (contra DDS HRAC Procedure Section 3(A)(2)(b), emphasis added). DDS should ensure that, in every placement review, the HRAC is considering whether the person can be appropriately served in a less-restrictive environment and recording the related finding in its minutes.

RCRC Review Q 3:

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 third quarter of Fiscal Year 2019:

- RCRC reviewed a total of 150 BSPs for 134 people.
 - All the reviews appeared to be non-emergency reviews of new BSPs (117; 78%) and updated BSPs (33; 22%).
- Of the BSPs reviewed, the vast majority were approved (140; 93%). A subset of these BSPs were approved for 30 days only (2 BSPs), 60 days only (1 BSPs), 90 days only (7 BSPs), and 6 months only (1 BSP).
 - 62 (41%) 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.¹¹
 - 2 (1%) of the BSPs reviewed were approved without clear RCRC answers to one or more of the 8 criteria being included in the minutes.
- 2 (1%) of the BSPs were rejected.
 - 7 (6%) of the BSPs were deferred.
 - All these BSPs that were deferred, rather than rejected, even though the RCRC answered “No” to one or more of the 8 required criteria.¹² More specifically, RCRC found:

¹¹ 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.”

¹² 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).

- In at least 3 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 targeted behaviors that were consistent with the person’s diagnoses.
 - 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.
 - In at least 1 of these cases, the BSP did not include demonstrated review of the data by the psychologist.
 - In at least 1 of these cases, the BSP did not include proactive and positive strategies
- The three most common restrictive controls reviewed within the BSPs were the use of psychotropic medications (within at least 146 or 97% of the BSPs), behavioral one-to-one aides (within at least 58 or 39% of the BSPs), and physical restraint (within at least 23 or 15% of the BSPs),
 - RCRC reviewed 4 requests for exemption from the requirement of having a BSP. All these requests 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 past recommendations. However, we remain concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- At least 47 BSPs (31%) 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 a review prior to that time.¹³
- At least 30 BSPs (20%) were approved, even if they referred to a restrictive control for which RCRC required further justification.
- At least 16 BSPs (11%) were approved, even though they referred to a restrictive control that RCRC expressly rejected or deferred.
- At least 3 (2%) of the BSPs reviewed was approved, even though RCRC indicated that one of the required criteria was not met

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 Q 4:

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 fourth quarter of fiscal year 2019 DDS provided Quality Trust with the minutes from HRAC meetings held on August 7, 2019, September 11, 2019, and September 25, 2019.

Based on the minutes provided during this quarter, the HRAC conducted 1 “systemic review of concerns” regarding an out-of-state residential provider. In addition, the HRAC reviewed 39 other human rights issues for 33 people – specifically:

- 20 issues (51%) were about Long-Term Acute Care (LTAC) placements.
- 8 issues (21%) were about out-of-state residential placements

¹³ 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.”

- 4 issues (10%) were about nursing home placements.
- 7 issues (18%) were about other human rights concerns, including those requests for exemption from fire drills, a request to remain in a one-bedroom residence, and a refusal to attend medical appointments.

This quarter, HRAC noted that it “remains concerned with the level of care Bridgepoint is providing to the people [DDA] support[s] who are [to be] weaned off a ventilator.” It went on to state that it “will review the data to determine if a systemic recommendation and further action is necessary.” Based on its monitoring and advocacy, Quality Trust also has concerns about the quality of care Bridgepoint provides. Quality Trust requests that DDS coordinate with the DC Department of Health (DC Health) and the Department of Health Care Finance, so that a systemic review of Bridgepoint is conducted, and appropriate corrective action taken to ensure the health and safety of people with intellectual and developmental disabilities who are served there.

RCRC Review Q 4:

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 fourth quarter of Fiscal Year 2019:

- RCRC reviewed a total of 138 BSPs for 120 people.
 - All the reviews appeared to be non-emergency reviews of new BSPs (103; 75%) and updated BSPs (35; 25%).
- Of the BSPs reviewed, the vast majority were approved (120; 87%) were approved. A subset of these BSPs were approved for 30 days only (1 BSP), 45 days only (1 BSs), 90 days only (11 BSPs), and 6 months only (1 BSP).
 - 56 (41%) 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.¹⁴
 - 4 (3%) of the BSPs reviewed were approved without clear RCRC answers to one or more of the 8 criteria being included in the minutes.
- 2 (1%) of the BSPs were rejected.
 - 16 (12%) of the BSPs were deferred.
 - All these BSPs were deferred, rather than rejected, even though the RCRC answered “No” to one or more of the 8 required criteria.¹⁵ More specifically, RCRC found:
 - In at least 11 of these cases, the BSP did not include a rationale for using the restrictive interventions
 - In at least 5 of these cases, the BSP did not include targeted behaviors that were consistent with the person’s diagnoses.

¹⁴ 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.”

¹⁵ 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).

- In at least 5 of these cases, the BSP did not include a procedure 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.
- In at least 3 of these cases, the BSP did not include demonstrated review of the data by the psychologist.
- In at least 1 of these cases, the BSP did not include proactive and positive strategies
- The number and percentage of BSPs that were deferred this quarter were the highest of any prior quarter this fiscal year (Q1 = 5 or 3%; Q2 = 10 or 6%; Q3 = 7 or 6%; Q4 = 16 or 12%).
 - The three most common restrictive controls reviewed within the BSPs were the use of psychotropic medications (within at least 135 or 98% of the BSPs), behavioral one-to-one aides (within at least 64 or 46% of the BSPs), and physical restraint (within at least 40 or 29% of the BSPs),
 - RCRC reviewed 2 requests for exemption from the requirement of having a BSP. Both requests 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 past recommendations. However, we remain concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- At least 46 BSPs (33%) 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 a review prior to that time.¹⁶
- At least 32 BSPs (23%) were approved, even if they referred to a restrictive control for which RCRC required further justification.
- At least 6 BSPs (4%) were approved, even though they referred to a restrictive control that RCRC expressly rejected or deferred.
- At least 4 (3%) of the BSPs reviewed was approved, even though RCRC indicated that one of the required criteria was not met

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 fiscal year 2019 the HRAC reviewed a total of 161 human rights issues for 111 people. The primary issues reviewed were:

1. LTAC placements
2. Out of state placements
3. Nursing home placements
4. Rights restrictions

Based on our review of the meeting minutes Quality Trust in quarter four Quality Trust noted the following:

¹⁶ 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."

- In the fourth quarter, HRAC noted that it “remains concerned with the level of care Bridgepoint is providing to the people [DDA] support[s] who are [to be] weaned off a ventilator.” It went on to state that it “will review the data to determine if a systemic recommendation and further action is necessary.” Given that two people receiving services from DDS were placed at Bridgepoint where they remained for nearly a year each, and movement toward their discharge only occurred after intensive advocacy, Quality Trust requested that DDS coordinate with the DC Department of Health (DC Health) and the Department of Health Care Finance, so that a systemic review of Bridgepoint is conducted, and appropriate corrective action taken to ensure the health and safety of people with intellectual and developmental disabilities who are served there. We have received no indication from DDS leadership that such a review occurred.
- In the third quarter, the HRAC rejected placements for not being the least restrictive setting to meet the person’s needs on six occasions, and it deferred deciding on six occasions because of the need for more information related to the placement. However, in nine occasions this quarter, the HRAC approved a placement without expressly recording within its minutes that it had found the placement to be “the least restrictive and most appropriate settings to meet [the person’s] needs (contra DDS HRAC Procedure Section 3(A)(2)(b), emphasis added). We recommended that DDS ensure that, in every placement review, the HRAC is considering whether the person can be appropriately served in a less-restrictive environment and recording the related finding in its minutes.
- In the second quarter, we recommended HRAC engage in more thorough reviews 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. The HRAC minutes in that quarter reflected a more robust committee discussion when such placements were reviewed. For example, 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.
- We recommended in quarter one that the HRAC not 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.¹⁷ In such cases, it would be more consistent with DDS Procedure for HRAC to defer its determination until it receives an update.¹⁸

During fiscal year 2019 the RCRC reviewed a total of 636 BSP’s for 564 people. Based on our review of the meeting minutes our recommendations were:

Our consistent recommendation made in every quarter was that DDS more consistently implement its procedures for RCRC to reject or defer BSPs to ensure that that the person’s team does not implement the unrevised BSP that contains elements the RCRC found problematic and/or unjustified.

¹⁷ 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).

¹⁸ See *id.* at Section 3.A.3.f.ii.

Final Conclusions

The DD system in the District of Columbia is nearly three years removed from the *Evans* litigation. New realities are beginning to emerge regarding the scope, availability, and cost of services and supports. DDS is undertaking significant updates and changes to policy and procedure. Some of these changes were voluntarily initiated by the leadership, while others were driven by mandates put on all states by the Center for Medicaid and Medicare Services (CMS). Stakeholders have voiced concern about what they perceive are reductions in availability and increases in direct costs of services. Part of the concern rises from the poor outreach and collaboration exhibited by DDS leadership when they decided not to continue the DDS Health Initiative implemented through a contract with the DC University Center on Excellence in Developmental Disabilities (UCEDD) at Georgetown. Improved communication coupled with a greater sense of partnership between DDS, providers and people with disabilities is an area for improvement in the coming year. DDS launched two separate initiatives this Fiscal Year involving stakeholders in discussions about policy, practice and the near- and longer-term direction of services and supports in the District. These processes have not yet produced tangible results, but the trust developed by participation is a necessary step moving forward.

This report summarizes the varied activities in which Quality Trust has engaged as part of our overall monitoring plan for Fiscal Year 2019. This plan is reviewed and updated annually based on feedback about priorities from community stakeholders. As we have since 2003, all our efforts are focused on elevating the quality and responsiveness of services and supports to people receiving support through DDA. This year our focus on unplanned hospitalizations confirmed that the provider investigations of those incidents were properly conducted resulting in appropriate conclusions. We also found that there are still serious concerns with the quality of provider nursing services. This finding points to the need for more impactful monitoring by Service Coordinators. We will continue our follow-up for people placed in Long Term Acute Care Facilities (LTAC), the provision of healthcare to the nearly 2400 people comprising the DD system in the District as we remain concerned by the weakness in the health care system we continue to encounter. This report also notes the on-going issues regarding the work of DDS/DDA's Restrictive Rights & Control Committee (RCRC) and the Human Rights Committees. As with many aspects of DDA's work, there is much good to report, and there is also much room for growth and improvement if we are going to achieve the goal of a system that effectively supports people with disabilities and their families to live healthy and meaningful lives in the community.