



Fiscal Year 2017 Post Compliance Monitoring

Third Quarter
(April 2017-June 2017)

INTRODUCTION

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

This is the third quarter report of results from our monitoring during the period April 1st to June 30th, 2017. As we found in the first quarter, the statistical results of our random monitoring of 52 people this past quarter include positive findings in many areas. Additionally, the cumulative results through the past three quarters, and 125 individual reviews are also largely positive. There are some specific areas where clear improvement is indicated which are highlighted in this report. For instance, and as noted in prior post-compliance reports, we had seen improvements made to the Restrictive Controls & Rights Committee (RCRC) processes, as reflected in its minutes and in response to our prior recommendations. Nevertheless, we are concerned that RCRC may be approving plans that it should be rejecting or deferring. 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.

We note sustained improvement in areas such as: ensuring that ISP's are current, and ever-increasing use of the HCBS waiver over ICF/IDD congregate living arrangements, and ensuring people have relationships with people other than paid staff. This success is certainly welcomed and should be celebrated. And while these trends are positive overall, unfortunately as in previous quarters, we have encountered several situations at the individual level which cause concern about the quality of provider services, DDS Service Coordinator monitoring, and advocacy for specific people. In this report, we will describe a situation which highlights these issues for one person. We include this information because it demonstrates the types of issues (e.g. staff training and knowledge, nursing services and supports, and monitoring and ensuring provision of all services contained in the ISP by DDS Service Coordinators) that our data has repeatedly shown requires improvement. Enhancing these outcomes are essential in ensuring quality outcomes for people-especially those who require intensive supports and services.

Previously we described the fact that multi-level community based systems must be assessed at both the individual and systemic level. When single mistakes or sometimes multiple mistakes occur, their impact at the individual level can be devastating. Those mistakes viewed amid thousands of people receiving supports can appear less consequential. Our monitoring mission at Quality Trust is focused on analyzing how the larger system is or is not working. However, it is equally important that we also focus on the experience of each person and how action or inaction by people responsible for their health & wellbeing jeopardize their chances of living meaningfully alongside people without disabilities. As noted in our second quarter report, *“thinking of services from the inside out, those closest to the person, who we call Direct Support Professionals (DSP’s) MUST possess the skills they need, the judgment to react to unexpected changes, and direction of executive level staff at their provider agencies to ensure they are prepared. The same can be said for DDS, Service Coordinators in whom much responsibility for front line advocacy and monitoring are vested. Executive level staff at residential and day program providers and Developmental Disabilities Administration staff must ensure through rigorous Quality Improvement and Assurance (QI/QA) strategies that policy makers know, in real time what is working and what is not. When repeated failures that pose risk to people receiving supports and services are identified, interventions must be readily available to address their consequences.”* We add to that statement that available remedies when implemented must compel demonstrable and sustained improvement at the provider level or the remedies are diminished. As it asserts its independence after 41 years of court oversight, the government of the District of Columbia must ensure that QI/QA efforts, across government agencies work cohesively to ensure the health and wellbeing of all the approximately 2400 people receiving services and supports in Washington, D.C.

Methodology

The data contained in this report is broken down into the following sections: results from random sampling monitoring, Review and analysis of Serious Reportable Incidents (SRI’s), individual follow-up for placements in Long Term Acute Care (LTAC) facilities, results from Triaging and follow-up of Serious Reportable Incidents, analysis of reports provided to Quality Trust, updates to our involvement with people through advocacy, and finally data analysis and recommendations from our involvement with the DDS, DDA Restrictive Controls & Rights Committee and the Human Rights Advisory Committee.

To provide the most useful information to members of the City Council, families of people receiving services, providers and other advocates for people with developmental disabilities in the District of Columbia we set as our goal the completion of a statistically significant random sample of all people currently receiving services and supports; 2293. To attain the required level of certainty our sample will include 329 people. To further enhance the accuracy of our results we analyzed some basic demographic characteristics of the 2293 people; looking at gender, enrollment in the waiver, whether the person resides at home or in congregate living arrangements and whether the person resided at Forest Haven or not. Now that the Evans case has been settled we have decided not to present class status in our public reports, however we will continue to note that information in our database. The characteristics of our sample match the larger group of people receiving services within two percentage points; well within the margin of error.

Individual Monitoring

Total number of individual monitoring assessments completed and delivered to DDS: 52

- 75% (39) waiver
 - 50% (26) Supported Living
 - 4% (2) Residential Habilitation
 - 2% (1) Host Home
 - 19% (10) Natural Home
- 25% (13) not on the waiver
 - 23% (13) ICF
- 27% (14) had no day program
- Largest age group was 51-60 35%, followed by 21-30 at 25%
- 63% (33) were men
- 37% (19) were women
- 73% (38) walk independently
- 52% (28) can communicate with words
- 83% (43) had relationships with people other than paid staff
- 73% (33/45) of residential staff had all required trainings
- 85% (29/34) of day staff had all required trainings
- 35% (17/48) had problems with bowel elimination. The provider was consistently following recommendations to monitor bowel elimination 100% of the time.
- 25% (12/48) had a seizure diagnosis
- 35% (17/48) had hypertension
- 13% (6/48) had diabetes
- 25% (12/48) were overweight
- 45% (22/49) took no psychotropic medications
- 14% (7/49) took 1 psychotropic medication
- 22% (11/49) took 2 psychotropic medications
- 12% (6/49) took 3 psychotropic medications
- 2% (1/49) took 4 psychotropic medications
- 0% (0/49) took 5 psychotropic medications
- 0% (0/49) took over 5 psychotropic medications
- 4% (2/49) the number of medications could not be determined.
- 59% (29/49) took no seizure medications
- 27% (13/49) took 1 seizure medication
- 6% (3/49) took 2 seizure medications
- 96% (47/49) had a current physical
- 60% (28/47) had recommendations from their PCP implemented
- 79% (27/34) had dental recommendations implemented
- 76% (32/42) had a HCMP that referenced all their health needs (the N for this question is 42 because 10 people lived in natural homes or independent homes and did not have a HCMP)
- 81% (34/42) had a DSP that could describe their responsibilities. (the N equals 42 because 10 people lived in natural homes or independent homes and did not have a HCMP)
- 90% (37/41) staff were trained on HCMP updates (the N equals 41 because there were 11 people living in natural homes or independent living who did not have an HCMP or who did not have an updated plan)

- 58% (25/43) had staff that were knowledgeable of intended effects and side effects of medication
- 81% (42/52) DDS Service Coordinators ensured the delivery of services outlined in the ISP
- 67% (35/52) identified issues in monitoring tools. There were 12/52 (23%) instances where the QT monitor identified issues and concerns but no corresponding issues were identified in MCIS
- There were 5 people for whom our Monitors identified no issues (10%)
- 75% (39/52) required Service Coordination monitoring tools were verified by our Monitoring

Incidents and Their Investigations

During the third quarter of FY 2017 Quality Trust received 338 Serious Reports Incidents, (SRI's), an increase of 3 incidents from the second quarter, but an increase of 96 over quarter one. The following is a breakdown of those incidents by type.

Breakdown of incidents and percentages Q1, Q2 & Q3

Incidents Q1	Total Incidents	Percentage of total
Unplanned Emergency Inpatient Hospitalizations	91	(38%)
Neglect	46	(19%)
Serious Physical Injury	30	(12%)
Abuse	27	(11%)
Exploitation	22	(9%)
Death	15	(6%)
Missing Person	8	(3%)
Serious Medication Error	3	(1%)
Total	242	(100%)

Incidents Q2	Total Incidents	Percentage of total
Unplanned Emergency Inpatient Hospitalizations	122	(36%)
Neglect	96	(29%)
Abuse	33	(10%)
Serious Physical Injury	25	(7%)
Exploitation	22	(7%)
Missing Person	17	(5%)
Death	11	(3%)
Serious Medication Error	9	(3%)
Other	2	(<1%)
Total	337	(100%)

Incidents Q3	Total Incidents	Percentage of total
Unplanned Emergency Inpatient Hospitalizations	106	(31%)
Neglect	77	(23%)
Serious Physical Injury	53	(16%)
Abuse	39	(12%)
Exploitation	25	(7%)
Missing Person	17	(5%)
Death	8	(2%)
Serious Medication Error	6	(2%)
All Others	5	(1%)
Total	338	(100%)

Understanding Serious Reportable Incident data:

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

Unplanned Emergency Inpatient Hospitalizations (UEIH), were once again the highest category of incident in quarter three. The 106 UEIH's, while a decrease of 16, were still the single biggest category of Serious Reportable Incident. It is worth noting that while remaining the single highest category of incident, UEIH's as a percentage of overall incidents have decreased from 40-43% last year, to 31-38% this year.

Upon becoming a member in 2015, the Deputy Director of Programs urged the DDS, Quality Improvement Committee (QIC) to undertake a rigorous study of why people go to the emergency room in an unplanned manner. In early 2016, under the leadership of the Chair of the committee, a very small, and limited study of five people was undertaken by nurses from DDS' Health & Wellness Unit. The findings of this limited review indicated that basic things such as poor documentation and charting might be connected to instances of recurring hospitalizations for dehydration. As it was such a small study, no conclusions could be drawn, but the committee members decided a more thorough examination was warranted. In 2016, a committee member who at the time was Director of the DDA Health Initiative, Georgetown University Center for Child and Human Development, University Center for Excellence Developmental Disabilities, now retired, agreed that her organization would undertake such a study. Preliminary findings were present to the committee in draft form in the early summer of 2016. There were many questions raised about the accuracy of the data. The committee developed a list of questions and requests for clarification which was relayed to the researchers from Georgetown. The Chair of the committee has since left the employment of DDS, and the Director of the Georgetown initiative retired in August. To this date an updated draft report has

not been provided to the committee. Quality Trust views this as a significant opportunity lost, and we hope that the committee will complete such a study and disseminate the findings.

With three quarters of data now compiled, quarter one stands out as an anomaly. There were 242 incidents reported in that quarter whereas 337 and 338 respectively were reported in quarters two and three. So, for instance 46 incidents of neglect were reported in quarter one, while 96 were noted in quarter two, and increase of (109%). Conversely there was a reduction of neglect incidents from 96 to 77, or (20%) in quarter three. No explanation was provided for the dramatic, 109% increase in neglect incidents from quarter one over quarter two, nor the reduction this quarter. As a result, we have no explanation for either result. As we did in our quarter two report, once again, this quarter we request that DDS provide an analysis and explanation of the increase in quarter two, and reduction in quarter three. The number of neglect incidents substantiated remained high again this quarter. Of the 77 reported incidents, fully 52, or (67%) were substantiated. Over the past several quarters neglect is substantiated in most neglect investigations. We are not aware of any specific trainings or other interventions DDS has implemented to address the high number of substantiated neglect incidents. The third most numerous category was Serious Physical Injury, at 53 incidents. Fully 32 (60%) of those incidents were resolved without a finding of neglect or abuse. Again, since investigations of those incidents determined they were not the result of neglect or abuse, it is unclear if another explanation or explanations is offered. The 53 incidents of SPI were a significant increase from both quarters one and two where the numbers were 30, and 25 respectively. As with the findings for neglect, we have not received an explanation from DDS or analysis for these increases, or interventions aimed at lowering them.

In both the second and third quarters there was a doubling of SRI's in the Missing Person category from 8 in the first quarter, to 17 each in the second and third quarters.

After three quarters, the number of deaths stands at 34. There were 35 deaths during all of FY 2016. We have altered our monitoring process to include a visit to the home and day program by our team as soon as we receive notification. We will not complete that type of visit to a hospital or LTAC facility, but we will request information about them.

Serious Reportable Incident (SRI) Triage

Total number of incidents triaged: 303

UEIH: 98

- There was a (26%) decrease in the number of UEIH incidents from last quarter to this quarter from 132 to 98 this quarter.
- Results from triaging Unplanned Emergency Inpatient Hospitalizations:
 - 21 lived in their natural home
 - 43 received Supported Living
 - 28 in Intermediate Care Facilities (ICF/IDD)
 - 1 in a nursing home
 - 2 in Host Homes, and

- 3 in Residential Habilitation
- 60 out of 98 people (61%) had not experienced another UEIH incident in the past 6 months
- Out of the 98 incidents, 16 were involved psychiatric issues (16%)
- This finding is consistent with last quarter where we found 19/132 (14%).
- 3/16 (19%) went to Comprehensive Psychiatric Emergency Program (CPEP) for triage
- 6/16 (38%) involved the police
- 15/16 people (94%) had proper documentation authorizing the use of psychotropic medications, and
- 14/16 (88%) had a current Behavior Support Plan (BSP)
- People were admitted to the hospital with some commonly seen concerns/diagnosis. Seizure activity was the most commonly reported reason for unplanned visits this quarter
- The second highest diagnosis was breathing problems and pneumonia
- 14/98 (14%) people had previously been hospitalized with the same condition within the last 6 months

Number of people who had evidence of being admitted for a certain diagnosis/problem	Diagnosis/Concern
15	Seizures
10	Breathing problems
8	Pneumonia
5	Problems with G tube
5	Urinary Tract Infection
3	Vomiting
36	Other conditions, or unknown

All other SRIs: 205

- 32% (65/205) had prior serious reportable incidents within 60 days
- 17% (35/205) were abuse incidents
 - 9% (3/35) of the abuse incidents resulted in police involvement
 - 3% (1/35) of the abuse incidents resulted in someone going to the hospital
- 47% (72/205) were neglect incidents
 - 36% (26/72) of the neglect incidents were medical neglect
 - 93% (67/72) of the neglect incidents involved an allegation against provider staff
 - 3% (2/72) of the neglect incidents involved family
 - 1% (1/72) of the neglect incidents involved transportation providers
- 11% (22/205) were exploitation incidents
- 24% (50/205) were serious physical injuries
 - 90%(45/50) of the serious physical injuries were caused by accidents

- 18% (9/50) of injuries were caused by a behavioral health issue or episode. Six people had injuries from Self Injurious Behavior (SIB), and three from accidents during a behavioral episode
- 78% (7/9) of the people involved in a behavioral incident causing injury had a current BSP
- 11% (1/9) of the people involved in a behavioral incident causing injury had no BSP
- 11% (1/9) person involved in a behavioral episode causing injury had an expired BSP

SRI Follow Up

Total SRI follow up: 12

Incident Type	Number
UEIH	5
Neglect	2
Abuse	2
Serious Physical Injury	1
Inappropriate use of Restraints	1
Other	1

Unplanned Emergency Inpatient Hospitalizations (UEIH):

- All five people that had an UEIH had recommendations made at the time of discharge
- Recommendations for three of the people (60%) had been completed at the time of the visit
- Two people (40%) had the recommended follow up appointments scheduled but not completed
- All five people (100%) had been discharged back to their home at the time of the visit
- Only two people (40%) had returned to their day program at the time of the visit
Reasons for not returning included:
- Two people not been medically cleared, and
- One person had a team meeting scheduled to discuss necessary changes, but it had not yet been completed
- 100% of the people monitored had multiple UEIH incidents
- One SRI was generated after the visit for neglect. It was found that medical documentation was lacking and had not been updated following a hospitalization

Non-medical follow up:

- All people were deemed to be safe after the visit
- Three people had multiple incidents in the same category, and all three had plans developed to help reduce the likelihood of future incidents
- No new SRIs were generated after the visit

- One person received advocacy after the visit to ensure that new furniture was delivered to him

Serious Reportable Incidents (SRI's) generated by QT activities - 5

Incident Type	Generated through what QT activity
Exploitation	SRI follow up
Exploitation	SRI follow up
Exploitation	LTAC f/u- followed by advocacy
Neglect	Monitoring
Neglect	LTAC f/u- followed by advocacy

Long Term Acute Care (LTAC) Follow Up

Number of LTAC follow Up Visits: 10 (11 received, but 1 person was sent to Hospice instead of LTAC.)

- We received notification from DDS of 11 people going into LTAC, which is 100% notification.
- 2 people died. One person did not go to LTAC and died in hospice, another person died in the hospital after moving to a new provider. The other six people returned to their residential supports, which we verified through visits to ensure they had all the needed post discharge.

Reason for LTAC (note that people have multiple reasons)	Number of people
PT/OT/Speech	4
Antibiotics	3
Respiratory, Bi PAP machine	1
Ventilator	1
Gait problems	1

Advocacy

- People in active advocacy: 11
- Advocacy requests referred To Family Services: 0
- Outcomes Met or Closed: 6
- New Referrals: 5

Number of Outcomes Met	Outcome
1	Residential move or supports
3	Closed by the person/family/changed their minds

1	Financial support/change in SSI payee
1	Died

Referral Source	Number of referrals
Friend of the person	1
Provider	1
QT Attorneys	1
QT LTAC visit	1
QT SRI visit	1

Outcome requested	Number
DDA application support	1
Financial issues/help	1
Health/hydration concerns	1
Environmental/furniture	1
Help with getting supported living apartment	1

Restrictive Control Review Committee (RCRC) Review

Quality Trust reviews and analyzes the data from the meeting minutes of the Restrictive Control Review Committee (“RCRC”). This is an internal DDA committee which reviews Behavioral Support Plans (“BSPs”) to ensure restrictive controls within them are appropriately justified. These minutes are provided by DDS monthly.

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

- The RCRC reviewed a total of 195 BSPs for 185 people.
 - None of the reviews were identified as being made on an emergency basis.
 - 149 BSPs (76%) were identified as being new
 - 28 BSPs (14%) were identified as being an updated version
 - 18 BSPs (9%) were not specifically identified in the minutes as new or updated
- Of the BSPs reviewed, 187 (96%) were approved.
 - 59 (30%) of the BSPs were approved even though the RCRC minutes included substantive comments requiring the revision of the BSP¹ and/or raising issues that

¹ Under the DDS Guidance for RCRC Review of Behavioral Support Plans, available at <https://dds.dc.gov/node/803762>. BSPs plans that RCRC approves are supposed to be “acceptable as written and do not require further revision.”

called into question whether the BSP met the 8 required criteria listed in DDS' RCRC Procedure.²

- All BSP approvals were effective through the end of the current or next ISP year. Five BSPs (2%) were approved through the end of the ISP year even though they contained restrictions approved for only 90 days.
- Only 1 BSP was rejected
- 7 (4%) of the BSPs were deferred
 - 4 of these BSPs were deferred, rather than rejected, even though the RCRC answered “No” to one or more of the 8 criteria listed in DDS' RCRC Procedure.³
 - In one of these cases, RCRC had found that 4 of the required criteria were not met – i.e., that the target behaviors were not consistent with the listed diagnosis, that there was not a demonstrated review of the data by the psychologist, that the procedure to address the behavioral issues were not consistent with DDA policy, and that there was not a rationale for the restrictive intervention. Yet, the RCRC still did not reject the plan.
- The four most common restrictive controls reviewed were the use of psychotropic medications (within 183 or 94% of the BSPs), behavioral one-to-one aides (within 52 or 27% of the BSPs), physical restraint (within 18 or 9% of the BSPs), and “sharps restrictions” (within 14 or 7% of the BSPs).
- The RCRC reviewed 8 requests for exemption from the requirement of having a BSP. All of them were approved. There was 1 case an exemption request was approved with no rationale for the approval included within the minutes.

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

- 35 BSPs (18%) were approved until the end of the person's current or next ISP year, even though the RCRC minutes also indicated that the BSPs should be revised and re-submitted for an updated review prior to that time.

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

³ 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).

- 33 BSPs (17%) were approved even though they included a restrictive control for which the RCRC requested further justification.
- 5 BSPs (3%) were approved even though they included a restrictive control that the RCRC expressly rejected or deferred a decision on.

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

Human Rights Advisory Committee (HRAC) Review

Quality Trust receives, reviews and analyzes the data from minutes of the Human Rights Advisory Committee ("HRAC"). This is an internal DDA committee which reviews human rights issues arising within the DDA system. For this quarter, DDS provided us with the minutes from HRAC meetings held on April 26, May 24, and June 2 (an emergency meeting). DDS informed us that the meeting minutes for the June 28, 2017 meeting were in draft form and were not available until after they are reviewed and approved by the HRAC at their July meeting.

Based on the minutes provided, the HRAC reviewed 32 human rights issues for 23 people:

- 22 issues were about Long Term Acute Care ("LTAC") placements
- 2 issues were about nursing home placements
- 2 issues were about out of state placement
- 1 issue was about an institutional placement
- 1 issue was about a one-bedroom apartment
- 1 issue was about treatment refusal.
- 1 issue was about a Comfort Care Bracelet
- 1 issue was about use of protective mittens
- 1 issue was about a relationship/engagement

We have the following recommendations for improvements to the HRAC process:

- HRAC should only make recommendations on cases when there is a quorum, per its procedures.⁴ The HRAC proceeded with its meeting on May 24, 2017 without a quorum being met, for the stated reason that: "the majority of the scheduled reviews were updates to the committee." That is not a sufficient reason for proceeding without quorum, particularly given that the HRAC made decisions and recommendations at this meeting, including, for example, closing cases, requesting more information from service coordinators, and recommending an advocate be identified to assist with a human rights issue.

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

- HRAC should clearly document within its minutes whether it is approving, disapproving, or deferring the placements that it refers, including LTAC, nursing home, out-of-state, and institutional placements. The minutes we reviewed this quarter did not consistently do so.
- We are concerned that HRAC is not always being provided with the information that it needs to review placements in a timely way. There were at least 6 instances identified where the HRAC postponed its review because it had not received the information from DDS that it needed to conduct it. Two people had their placement postponed twice, meaning months were going by without a human rights review.

We also note that, at its April 26, 2017 meeting, HRAC reviewed the case of the person whose story is discussed below. At that meeting, HRAC closed this human rights review, noting he had been discharged from the LTAC to the ICF/IDD provider, the “SC report[ed] that his condition is improving,” and Quality Trust was involved. Given all the human rights issues that were involved in that case and discussed below, that closure decision raises questions as to how meaningful the HRAC review of his circumstances were.

One Person’s Story

Fred was not his real name. We are telling his story because it illustrates features of care we have encountered for him and other people which cause us concern. When he was born people with I/DD had little opportunity to receive supports at home or in small congregate settings. In 1982, he moved to a community home with supports & services through what was then one of the most respected providers in the District. Fred continued to be supported by that provider for the next 35 years, until early this year.

In late 2016 and early 2017, as he reached 60 years of age his health began to decline significantly. Throughout his early and middle years, he was not a person that required a great deal of nursing or behavioral health supports. In that sense, he required a provider confident and competent enough to not overserve him. As he approached 60 years of age though, his health needs increased dramatically and quickly as well.

In March of 2017, we received a notification that Fred had been placed in a Long Term Acute Care Facility (LTAC). A routine visit was made to follow up on the supports he was receiving, and to check on his overall health and wellbeing. On this occasion the Monitoring Coordinator, with whom he had a relationship in this past made the visit. It was discovered during this visit that because of the significant decline in his health, DDS determined that upon discharge from the LTAC he would move from his waiver funded living situation to an ICF/IDD. The provider with whom he had lived for 35 years does not operate ICF/IDD homes, so a transfer to a new provider was necessary. On March 26, 2017, we emailed the team to let them know we were following Fred, and would do so as his advocate to ensure his transition from the LTAC to the new provider was successful.

During our initial visit to his new home we noted a lack of documentation and the inability of his nurse to answer our questions. It appeared to us that large amounts of his historical record (which should have accompanied him) had not accompanied him to the new home. When we asked questions of his 1:1 LPN (whose main function was to ensure that his medical and

nursing needs were being met and documented), she provided only partial, or in some cases no information. The QDDP of the home informed us that his Interdisciplinary Team (IDT) was planning a meeting to address his health status post discharge from the LTAC, and his new placement in the ICF. Despite emails to the QDDP and DDS Service Coordinator requesting we be made aware of the date and time of the meeting, we did not receive timely responses. So, on April 26, 2017, we reached out the Chief of Service Coordination requesting his help. We received a response from the Deputy Director of DDA later that day thanking us for sending our concerns, and letting us know that his team would discuss it and respond to us.

On May 19, 2017, when the meeting did occur, the main agenda item discussed was the team's inability to locate a dementia screening. Screenings are recommended by the DDS Health & Wellness Standards every year for people with Down syndrome beginning at 40 years of age. As he was 60 and had Down Syndrome, the lack of such a screening was concerning to the team. It was possible that one had not been done, or it was possible that it was not included in the medical records made available to the new provider and thus the team. The issue was of significant enough concern that the Director of the DDA Health Initiative attended the meeting to ensure that either the document was located, or an appointment made for an MRI of his brain. In response to receiving a draft of this report DDA made available what it characterized as a Dementia Screening completed in March of 2017. It is telling that apparently the Service Coordinator and the Director of the DDA Health Initiative were unaware that such a screening had been completed since at the meeting on May 19, 2017, they were advocating for its completion. The team arranged for a screening to be completed on June 9, 2017. During the meeting, the QT advocate outlined multiple other issues she had discovered during her review of his records. These included lack of a proper wheelchair, and no urgent effort between the provider and Service Coordinator to obtain one; missing medical documentation - both historical from the prior provider and from the current provider; widely differing weight readings due to a broken scale; interviews with the nurse assigned causing concerns that she was unable to describe his current or historical medical issues; and lack of consistent and timely documentation of the supports being provided at the facility. We notified DDA senior leadership of our concerns and the lack of urgency displayed by the Service Coordinator to respond to them. By May 23, 2017 we had not received a response, so we notified the Department of Health, Health Regulation & Licensing Administration (HLRA), the government agency responsible for licensure and enforcement of ICF/IDD's. On May 26, 2017, HRLA visited the home and notified the provider that the home had been placed in Immediate Jeopardy emanating from the issues involving Fred's care. The Immediate Jeopardy was lifted on June 6, 2017, however HRLA noted that lower level deficiencies remained. Ultimately the provider could demonstrate that they had rectified all outstanding issues, and all conditions of participation were lifted.

The specific events leading up to Fred's significant health decline however began when his long-time provider, with whom he had a 35-year history appears not to have acted with urgency when he had developed a serious urinary tract infection that had turned into sepsis. The documentation from the physician at his admission to the ER on February 15, 2017, state, "patient presented with a history of vomiting and maroon colored stools one day prior." Despite his vomiting and discolored stools over a 24-hour period then, he was sent to his day program rather than to his physician or the hospital. The staff from the day program called 911 when upon returning from a community outing, he vomited several times. When he arrived at the hospital he was diagnosed with sepsis secondary to a urinary tract infection, GI bleeding and an acute renal injury. The investigation of this unplanned hospitalization was completed by the day

program since that it was they who called 911 which initiated his unplanned emergency hospitalization. The provider determined that the hospitalization was not due to abuse or neglect on their part. The DDA, Incident Management & Enforcement Unit (IMEU) did not participate in completing the investigation, but did review it for quality. In faulting the investigation for not being sufficiently thorough, they noted that it did not include proper review of records and interviews at the residence or the statement by the admitting physician. By including that statement, one might assume a more complete investigation into the actions of the residential provider would have been undertaken. To the contrary not only was such an investigation not undertaken, but IMEU also found that the hospitalization was not a result of abuse or neglect. This raises concerns. If Fred, “presented with vomiting and maroon colored stools one day prior to arrival...secondarily found to have acute kidney injury secondary to gastrointestinal bleed.” we contend that investigation should have been initiated and we question why a rigorous look at the nursing services provided by the residential provider was not completed.

Fred had been hospitalized for approximately one month before a g-tube was inserted to make the provision of hydration and nutrition easier and more precise. He received antibiotics to resolve the UTI, and despite the g-tube, he again became dehydrated. Further complicating matters, he also had acquired a pressure sore. At this point, the hospital characterized his condition as stable and he was transferred to the LTAC where he remained for three weeks. While there, his family chose the provider after being given the name by the DDS Service Coordinator. The Intermediate Care Facility is considered a medical model of group home designed specifically for people with elevated or complex medical and nursing needs.

The day he was discharged to his new home and provider, he was immediately returned to the hospital where he was once again diagnosed with dehydration, and admitted for several days. The reoccurrence of dehydration at the LTAC is particularly concerning. We could find no documentation that the Service Coordinator lodged any complaints, or elevated these issues to a superior, the DDA Health & Wellness unit, or anyone from QI/QA at DDA. Once again, he was discharged back to his new home. Fred became dehydrated several more times at his new home despite receiving hydration from a G-tube, and eventually was sent back to the hospital with pneumonia. During this hospitalization, he experienced the same poor outcomes as he had during his first: receiving antibiotics, acquiring another pressure sore and once again becoming dehydrated.

Our intervention in his life brought about intensive intervention by DOH, HRLA, and DDS, DDA. One of the first actions taken by DDA was to send a team of nurses to buttress the work we had begun. The reviews completed by the DDA nurses resulted in the filing of multiple Serious Reportable Incidents (SRI's) for neglect and exploitation. It is disappointing and concerning that the visits made by the Health & Wellness nurses were not initiated by monitoring and advocacy by the Service Coordinator, but by the actions of QT and HRLA. This, more than any other factor causes us great concern.

In June of 2017 Fred passed away. Nothing in Fred's story is offered as causal evidence for his death. What we are suggesting is that several key issues should be looked at to ensure that everything that can be done will be done for all people experiencing a decline in health. This death will be investigated by a third-party, independent investigation team that will produce formal findings, conclusions and recommendations as part of the District's Quality Assurance system. This will be further reviewed by both DDA's internal Mortality Review Committee and the city-wide Fatality Review Committee. This process can take six to twelve months to complete. An independent review such as will be completed by the Columbus organization is an important component of the DDS QA/QI process. That review however is colored by the amount and relevancy of the information it receives, and as noted, the entire process takes several

months to complete. For its timeliness and independence, advocacy and monitoring such as performed by Quality Trust in this case is equally crucial for the protection of health and wellbeing of people receiving services and supports in the District of Columbia. We offer the following as issues DDS should consider in order to better ensure quality health outcomes for people experiencing complicated health and/or behavioral or mental health declines.

- Once the admitting statement of the physician was known, why didn't IMEU launch an investigation of the nursing supports provided by the residential provider?
- Since a Dementia screening had been completed in March 2017, why wasn't it shared with the Service Coordinator, the Director of the DDA Health Initiative and the new provider by May of 2017 when they held a meeting to ensure one be located or completed?
- DDA staff do not govern the course or quality of care in hospitals or LTAC facilities, but outreach to these types of facilities must continue to ensure that people receive the highest quality of care.
- Oversight of Service Coordinators should be sharpened to ensure that the kinds of issues presented are discovered by them before any outside organization.

Conclusion

Once again, this quarter overall results from our monitoring indicate that compliance is being maintained in several areas. After several quarters of compiling and reporting on this data one thing is clear: areas of strength remain strong, while areas needing improvement continue as well. For instance, use of the waiver, at 75% is in keeping with findings in all our previous reports. The fact that 83% of people reviewed had relationships with someone who is an unpaid staff is also a very promising trend. Nearly everyone, 96% had a current physical, and 100% had a current ISP.

At the same time, areas where performance is low have remained unchanged. The continued low performance is a cause for concern. While issue related to the quality of healthcare provided in hospitals and LTAC facilities is somewhat out of the direct control of DDS, the performance of their Service Coordinators and incident Investigators and the providers with whom they contract are not, so interventions are well within the mandate of the QI/QA system and should therefore be undertaken to ensure the health and wellbeing of all the approximately 24 people in the DD system in the District of Columbia.

Finally, we draw attention to the limits of legal advocacy through the commitment process for people with intellectual disabilities. The notion that people are committed through a court process (e.g. have their rights to make decisions about placement and services removed) is antiquated, linked to institutional models of care and in conflict with the spirit if not the letter of the HCBS Waiver model widely used in DC. In fact, per DDS only 16 such commitments have been initiated since 2010. So, very few people newly entering the system are committed. It is long past time to change the law and focus attention on improving the safeguards and systems for quality within the government and provider systems.

