



4th Quarter Data

(July 1, 2017-September 30, 2017)

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 District of Columbia (DC), Department of Disabilities Services (DDS), Developmental Disabilities Administration (DDA).

This is the fourth quarter report of results from our monitoring during the period July 1st to September 30th, 2017. Individual monitoring reports for 223 people over four quarters are now complete. Our statistical findings during this quarter are particularly strong across a wide range of categories. This sample represents the first part of a two-year effort to complete individual monitoring for a statistically significant number of people receiving supports and services in DC.

The data this quarter is particularly encouraging as areas which had been relatively weak showed improvement, in some cases significantly. Areas such as current staff training, timely follow up on recommendations from physicians, current and accurate content in Health Care Monitoring Plans (HCMP) all showed improvement. We also 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.

We also looked very specifically at whether the DDS Service Coordinators are ensuring that services and supports listed in the ISP are being implemented as needed this quarter. The finding that 85% of Service Coordinators fulfilled expectations is encouraging. Engagement at the level necessary to ensure needed services are in place is an important component of the Service Coordinator's involvement with the people they support. Ensuring good outcomes often requires enhanced engagement, and is essential -- especially for people who require complex and/or intensive supports and services.

We have previously described how multi-level community based systems must be assessed at both the individual and systemic level. When single mistakes or omissions 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 protocol at Quality Trust is focused on analyzing how the larger system is or is not working. However, given our advocacy mission, 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 & well-being may jeopardize their chances of living meaningfully alongside people without disabilities. While the above noted trends are generally positive, 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.

Methodology

The data contained in this report is broken down into the following sections: results from random sampling individual 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 which was 2293 people at the onset of this project. To attain the required level of certainty our final 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

Monitoring

Total number of monitoring assessments sent to DDS: 46

Total number of people monitored who had a nursing review: 42

Total number of people monitored through four quarters: 223

Demographics

- 85% (39) waiver
- 15% (7) not on the waiver
- 9% (4) ICF
- 46% (21) Supported Living
- 9% (4) Residential Habilitation
- 11% (5) Host Home
- 22% (10) natural home
- 25% (15) had no day program
- Largest age group was 21-30, 29%,
- followed by 61-70 at 24%
- 65% (30) were male
- 35% (16) were female
- 74% (34) walk without assistance
- 57% (28) communicate using words

- 87% (39) had relationships with people other than paid staff

Staff Training

- 90% (38/42) of residential staff had all required trainings
- 82% (28/34) of day staff had all required trainings
- 71% (25/35) had a DSP that could described their responsibilities (Not all people have staff support.)
- 79% (26/33) had staff that were knowledgeable of intended effects and side effects of medication (Not all people had staff and or medication, I.E. natural homes, independent living)

Medical/Nursing Profile

- 5% (2/42) had choking precautions in place
- 17% (7/42) had bowel elimination problems
- 36% (15/42) had a seizure diagnosis
- 48% (20/42) had hypertension
- 19% (8/42) had diabetes
- 38% (16/42) were overweight

Behavioral Health/Use of Psychotropic Medications

- 50% (21/42) took no psychotropic medications
- 17% (7/42) took 1 psychotropic medication
- 5% (2/42) took 2 psychotropic medications
- 10% (4/42) took 3 psychotropic medications
- 14% (6/42) took 4 psychotropic medications
- 5% (2/42) took 5 psychotropic medications
- 0% (0/42) took over 5 psychotropic medications

Use of Neuroleptic Medication

- 56% (24/42) took no seizure medications
- 33% (14/42) took 1 seizure medication
- 5% (2/42) took 2 seizure medications
- 95% (40/42) had a current physical

Follow -up on medical recommendations

- 82% (23/28) had recommendations from the PCP implemented (only 28 people had recommendations from their PCP.)
- 93% (25/27) had dental recommendations implemented (only 27 people had recommendations made by their dentist,)
- 86% (30/35) had a HCMP that referenced all their health needs (Natural homes are not required to have HCMP)

DDS Service Coordinator Performance

- 85% (39/46) DDS Service Coordinators ensured the delivery of services as outlined in the ISP
- 85% (35/41) identified issues in monitoring tools (not all people had obvious issues that required identification.)
- 89% (41/46) completed monitoring tools as required

Advocacy

People in active advocacy: 28

Advocacy requests referred to Family Services: 0

Outcomes Met or Closed: 9

New Referrals: 9

Number of Outcomes Met	Outcome
2	Residential move or supports
2	Closed by the person/family/changed their minds
1	Provider changed funding stream so person could stay with them
1	Medication issues resolved
1	Follow up on neglect, extermination for insects completed
1	Intake to DDA completed
1	Day program started

Referral Source	Number of referrals
Friend/family of the person	4
DDS SC	1
QT Attorneys	2
QT LTAC visit	1
APS	1

Outcome requested	Number
DDA application support	2
Follow up with concerns regarding provider	1
Health concerns	1
Residential change	1
Safety concerns	1
Employment help	1
Help with RSA	2

Long Term Acute Care Facility Placement (LTAC) Follow Up

Number of LTAC follow Up Visits: 7

- We received notification from DDS of 7 people going into LTAC. That is 100% notification.
- 1 person received ongoing advocacy due to a change in the level of care and subsequent new residential placement.

Reason for LTAC (note that people have multiple reasons)	Number of people
PT/OT/Speech	3
Antibiotics	1
dialysis	2
Fluid on brain to be removed	1
Wound care	1

Serious Reportable Incident (SRI) Follow Up

Total SRI follow-up: 7

Incident Type	Number
UEIH	5
Neglect	1
Abuse	1

Unplanned Emergency Inpatient Hospitalization (UEIH):

- 4/5 (80%) people that had UEIH had recommendations made at the time of discharge.
 - 4 people (100%) had the recommendations completed at the time of the visit.
- 4/5 people (80%) had been discharged back to their home at the time of the visit. One person went to LTAC.
- 3/5 people (60%) had started back at their day program at the time of the visit. Reasons for not returning included two people who needed a team meeting scheduled to discuss necessary changes, but it had not been completed yet.
 - 4/5 (80%) of the people seen had multiple UEIH incidents.
 - No new SRIs were generated after the visit.

Non-medical follow up:

- All people were deemed to be safe after the visit.
- 1 (50%) people had multiple incidents in the same category, and non (0) had plans developed to help reduce future incidents.
 - No new SRIs were generated after the visit

1 person received advocacy after a follow-up visit to ensure a residential placement after respite

Incidents and Their Investigations

During the fourth quarter of FY 2017 Quality Trust received 425 Serious Reports Incidents, (SRI's), an increase of 87 incidents, or (26%) from the third quarter. The following is a breakdown of those incidents by type.

Breakdown of incidents and percentages Q1 –Q4

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%)

Incidents Q4	Total Incidents	Percentage of total
Unplanned Emergency Inpatient Hospitalizations	120	(38%)
Neglect	82	(26%)
Abuse	43	(13%)
Serious Physical Injury	37	(12%)
Exploitation	18	(6%)
Missing Person	10	(3%)
Death	5	(2%)
Serious Medication Error	2	(<1)
All Others	2	(<1)
Total	319	(100%)

Analysis of 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 have the greatest 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 all four quarter of FY 2017. The chart further delineates the percentage of the total of all incidents.

Unplanned Emergency Inpatient Hospitalizations (UEIH) were once again the highest category of incident in quarter four. This continues a trend that has been sustained over multiple quarters and years. The 117 UEIH's, accounted for (37%) of all incidents in the fourth quarter of FY 2017. As we noted in our last report, 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. Despite that finding, it remains a significant concern that nearly one in four incidents in the District involves an unplanned hospital admission.

We again urge the DDS Quality Improvement Committee to complete a review of unplanned hospitalizations and share the information with the advocacy community. The specific reasons why UEIH occur at the current frequency are unknown. Also unknown is how this frequency compares with other systems supporting people developmental disabilities throughout the country. Quality Trust remains disappointed that such a review has not been completed by the committee. This review could provide valuable insight into how health care is utilized by people in the system and potentially how health supports could be further improved. Data from urban areas, broken out from state level data is difficult to access, so reporting of this kind could make the District a bellwether in analysis of such data.

With four quarters of data now compiled, quarter one stands out as an anomaly. The reasons for the relatively low number of incidents reported in that quarter are not clear, especially since there has been a steady and significant increase in every quarter since. There were 242 incidents reported in quarter one compared to 319 this quarter, an increase of (32%). Except for death where the number of incidents decreased dramatically, incidents reported in all other categories increased significantly. For instance, the 46 incidents of neglect reported in quarter one more than doubled to 82 this quarter. Despite our requests for analysis from DDA regarding these increases, decreases, trends and any training initiatives resulting from such an analysis we have received no response to date. Further analysis of the data reveals that the percentage of substantiated incidents is extremely low in every category except neglect. For instance, only 5 of the 120 unplanned hospitalizations were found to be a result of neglect (4%). In the category of Serious Physical Injuries, we have no context in which to judge the fact that 14 of 37 (38%) were substantiated for neglect or abuse. DDS has provided no other explanations. In the category of abuse, 10 of 43, or (23%) incidents were substantiated. Alternative explanations for the other (77%) have not been shared. Only in the category of neglect, where 46 of 82 incidents or (56%), was there a finding of substantiation. When looking at all 1236 incidents reported for FY 2017, only 250 or (20%) were substantiated for abuse or neglect. What remains is a combination of incidents being resolved with no finding, inconclusive findings, or administrative closure for the roughly (80%) of incidents reported during the past year. An analysis by DDS of the low percentage of substantiation and/or alternative explanations across all incident categories would appear to be warranted. This type of analysis may also identify additional needs for training and education for staff throughout the system.

Restrictive Control Review Committee (RCRC) Review:

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

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

- The RCRC reviewed a total of 150 Behavioral Support Plans (“BSPs”) for 140 people.
 - Most reviews were identified as non-emergency reviews of new BSPs (126; 84%) and updated BSPs (16; 11%). One (1) BSP was identified as being a “New Update.” One (1) BSP was not specifically identified in the minutes as new or updated.
 - Five (5) BSPs (3%) were identified as being reviewed on an emergency basis, and one (1) BSP review was a “Follow-up from Emergency.”
- Of the BSPs reviewed, 138 (92%) were approved.
 - 37 (25%) of the BSPs were approved even though the RCRC minutes included substantive comments requiring the revision of the BSP and/or raising issues that called into question whether the BSP met the 8 required criteria listed in DDS’ RCRC Procedure.¹

¹ 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

- 5 (3%) of the BSPs were rejected.
- 7 (5%) of the BSPs were deferred.
 - Five (5) 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.
 - In one of these cases, RCRC had found that 3 of the required criteria were not met – i.e., that the procedure to address the behavioral issues was not consistent with DDA policy, that there was not a rationale for the restrictive intervention, and there were not benchmarks for reducing restrictive interventions including a titration plan. Despite all of those discrepancies the RCRC did not reject the plan.
- Like in the third quarter, the four most common restrictive controls reviewed were the use of psychotropic medications (within 140 or 93% of the BSPs), behavioral one-to-one aides (within 66 or 44% of the BSPs), physical restraint (within 21 or 14% of the BSPs), and “sharps restrictions” (within 12 or 8% of the BSPs).
- The RCRC reviewed eleven (11) requests for exemption from the requirement of having a BSP. All were approved.

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 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:

- 22 BSPs (15%) 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.
- 26 (17%) of the BSPs were approved, even though they referred to a restrictive control that the RCRC expressly rejected, deferred approval, or required further justification for.

Once again, we note that it would appear to be more consistent with the intent of its procedures for the 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 analyzes the data from minutes of the Human Rights Advisory Committee (“HRAC”), which reviews human rights issues arising within the DDA system. For the fourth quarter, DDS provided us with the minutes from HRAC meetings held on July 26 and August 23, 2017. DDS postponed the monthly HRAC meeting originally scheduled for September 27, 2017 to October 6, 2017, so data from a September meeting is not included within this report for the fourth quarter.

rational for using the restrictive interventions? (8) Are there benchmarks for reducing the restrictive interviews 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.”

Based on the minutes provided, during the fourth quarter, the HRAC reviewed 17 human rights issues for 10 people:

- Ten (10) issues involved Long Term Acute Care (“LTAC”) placements
- Four (4) issues were about nursing home placements
- Two (2) issues concerned an audio monitor
- One (1) issue was listed as “unknown” and closed after no additional information after the initial request was submitted to HRAC

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

- We previously recommended that HRAC clearly document within its minutes whether it is approving, disapproving, or deferring the placements that it reviews, including LTAC, nursing home, out-of-state, and institutional placements. While this quarter’s HRAC minutes reflected marked improvements in this regard, there were cases in which clear determination still was not included in the minutes, and so we urge the HRAC to fully implement this systems improvement going forward.
- DDS should ensure that there is a robust tracking system for cases that come before the HRAC, as well as adequate safeguards in place to prevent the premature closure of such cases. For example:
 - On July 26, 2017, a case came before the HRAC for a person whose human rights issue was listed as “unknown.” The HRAC closed the case because “no information [was] submitted to [the] committee,” after the initial request to schedule a review. Yet, a search of Quality Trust’s HRAC tracking spreadsheet indicated that the issue may have been about a one-bedroom apartment that was approved by HRAC on April 26, 2017, and that was due for a quarterly review by HRAC.
 - On July 26, 2017, a case involving a person who was waiting to be discharged from a nursing facility was reviewed by HRAC. During that review, it was noted that an ICF provider had been identified, but the discharge from the nursing facility was pending receipt of additional adaptive equipment, including a fitted wheelchair. At its August 23, 2017 meeting, the HRAC noted that the discharge was still pending receipt of adaptive requirement. Yet, the HRAC closed the case, concluding “no further review was needed.” Delays in receipt of adaptive equipment that result in people remaining in overly restrictive living environments instead of community-based placements are serious human rights issues that warrant continued HRAC monitoring, review, and intervention.
- The HRAC should clearly document within its minutes when its next review date of an approved placement will be. This will ensure that it has clearly “establish[ed] the expectation for on-going review,” as required by Section 3(A)(3)(f)(i) of the HRAC Procedure.

Conclusion

Our findings in many areas this quarter are positive. Measures in categories such as staff training, up to date HCMP’s, current ISP, use of the waiver, etc., demonstrated substantial compliance with expectations. Requests for advocacy remained consistent with previous

quarters, and the types of intervention needed was also similar. Seven people were admitted to LTAC's, and we received notification from DDS as required for all of them. The reasons for the admissions were in line with admissions in the past. Seven people were visited in the wake of Serious Reportable Incidents being filed on their behalf. Five people had an unplanned hospitalization, and two were the victims of alleged abuse and neglect. Our follow up visits to those seven people revealed that their DSS Service Coordinators were engaged, and documented their supports in progress notes.

The incident management and investigation system is a critical element of the system for ensuring the health & wellbeing of people within the service system. We remain concerned about the number of unplanned hospitalizations, and the reluctance of DDS to conduct an analysis that can establish context for the frequency of incidents, look at potential root causes, and provide recommendations for changes in practice where indicated. We are also concerned by the relatively small percentage of incidents for which a causal connection to either abuse or neglect is made. Further analysis by DDS in this area also seems warranted. The goal of this analysis should be to identify reasons for the low percentage of substantiation as a final outcome of investigations. Additional training for provider and/or IMEU staff may be required to ensure that the investigation process results in clear conclusions, especially when facts conflict or contradict, as they frequently do.

Finally, we note that we will continue to complete individual monitoring for an additional 106 people in the coming quarters to achieve our goal of having collected data from a statistically significant random sample of all people currently receiving services and supports in DC. This sample will allow us to have greater confidence that the conclusions based on our monitoring results are truly reflective of the actual experiences of people supported within the DDS/DDA system. We will conduct an overall analysis using the full sample when it is completed in the coming year.