1st Quarter Data

(October 1, 2017-December 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 advocate and mechanism, through monitoring and other services for safeguarding all people with intellectual and other developmental disabilities served by the District. It was always contemplated that Quality Trust would 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.

We are into our fifth quarter of gathering data regarding compliance with court orders in the *Evans* case. We are reaching the end of the work; having completed 271 of the required 329 reviews required to arrive a statistically significant finding about the quality of services provided to the approximately 2300 people in the DD system in the District of Columbia. Through five quarters our findings indicate compliance is being maintained. At the same time, these five quarters have provided numerous situations where the system underperformed for individual people. In this report we will analyze both positive and negative aspects of the current state of things, and offer our thoughts on where things need to go to elevate the system from one of measuring compliance to ensuring high quality supports and services which should be the goal.

A milestone was reached on January 7th, 2018. That was the one year anniversary of the conclusion of the Evans case. With that milestone reached it is time for the system to move beyond the compliance model that served it well in exiting the case. It is now incumbent for all District government agencies involved in the provision, licensing &regulation and funding of DD services to reach toward a higher goal. In this report we will provide examples that point to the need for a greater commitment to looking at people one at a time, rather than as members of various groups, for it only though such individualized focus that truly positive outcomes will be reached for everyone on the system.

Individual Monitoring

Monitoring

Total number of monitoring assessments sent to DDS: 48

Total number of people monitored who had a nursing review: 32

Total number of people monitored through five quarters: 271

Demographics

- 79% (38) waiver
- 21% (10) not on the waiver
- 15% (7) ICF
- 40% (19) Supported Living
- 6% (3) Residential Habilitation
- 2% (1) Host Home
- 33% (16) natural home
- 38% (18) had no day program
- Largest age group was 51-60, 25%,
- 60% (29) were male
- 40% (19) were female
- 71% (34) walk without assistance
- 43% (26) communicate using words
- 90% (43) had relationships with people other than paid staff

Staff Training

- 84% (37/44) of residential staff had all required trainings
- 79% (23/29) of day staff had all required trainings
- 95% (25/27) had a day DSP that could describe their responsibilities (Not all people have staff support.)
- 93% (25/27) had a home that could describe their responsibilities. (Not all people have day staff.)
- 67% (24/33) 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

- 3% (1/32) had choking precautions in place
- 47% (15/32) had bowel elimination problems
- 47% (15/32) had a seizure diagnosis
- 44% (14/32) had hypertension
- 9% (3/32) had diabetes
- 50% (16/32) were overweight

Behavioral Health/Use of Psychotropic Medications

- 50% (21/42) took no psychotropic medications
- 15% (5/33) took 1 psychotropic medication
- 12% (4/33) took 2 psychotropic medications
- 6% (2/33) took 3 psychotropic medications
- 6% (2/33) took 4 psychotropic medications
- 6% (2/33) took 5 psychotropic medications
- 0% (0/33) took over 5 psychotropic medications

Use of Neuroleptic Medication

- 50% (16/32) took no seizure medications
- 28% (9/32) took 1 seizure medication
- 19% (6/32) took 2 seizure medications
- 3 %(1/32) took 3 seizure medications

Follow -up on medical recommendations

- 86% (25/29) had recommendations from the PCP implemented (only 29 people had recommendations from their PCP.)
- 96% (23/24) had dental recommendations implemented (only 24 people had recommendations made by their dentist,)
- 87% (27/31) had a HCMP that referenced all their health needs (Natural homes are not required to have HCMP)

DDS Service Coordinator Performance

- 38% (18/47) DDS Service Coordinators ensured the delivery of services outlined in the ISP (1 person was not available to the SC and was in the process of being dropped by DDS.)
- 44% (21/48) identified issues in monitoring tools (not all people had obvious issues that required identification.)
- 67% (32/48) completed monitoring tools as required

Concluding Comments

It is interesting that many of the demographic data has remained remarkably consistent over these five quarters, and beyond. For instance, use of the waiver, percentages of women compared to men, and types and locations of services; both day and residential have remained consistent plus or minus a couple points.

Staff training has seen an increase, which is a very promising development. While we will show individual shortcomings in that area in this report, the fact that 90+% direct staff could answer questions about their responsibilities is remarkable. In samples from 2013, the level of compliance was in between 65-75%. Further, our finding that 86% & 96% respectfully of people's medical and dental recommendations were implemented in the timeframe required. The 87% of people who had a Health Care Management Plan which referenced all their health needs is also encouraging.

The results for Service Coordinators monitoring and ISP follow up is very concerning, however. The DD system in the District is led by the Service Coordinators who work for DDS. Their role is multilevel; at once an advocate, at another a monitor. Highly effective Service Coordinators can mean the difference between timely, high quality support, or failing to get the help you need in the time you need it. It is essential DDA think creatively about how Service Coordinators maintain a highly effective role in the lives of people supported through DDA.

Advocacy

People in active advocacy: 28

Advocacy requests referred to Family Services: 1

Outcomes Met or Closed: 7

New Referrals: 6

Number of Outcomes Met	Outcome
3	Residential move or supports
1	Closed by the person/family/changed their minds
1	SSI reinstated
1	DDS Service Coordinator changed
1	Increased supervision at day program

Referral Source	Number of referrals
Friend/family of the person	2
SOME/outside agency	1
QT Attorneys	0
QT LTAC visit	1
SRI follow up	2

Outcome requested	Number
DDS SC change	1
Increased supervision after incident	1
Request to permanently stay with respite provider	1
Residential change	2
Reinstate SSI	1

LTAC Follow Up

Number of LTAC follow Up Visits: 11

- We received notification from DDS of 11 people going into LTAC. That is 100% notification.
- 2 people received ongoing advocacy due to a change of level of care to hospice and one person having ongoing guardianship concerns

Reason for LTAC (note that people have multiple reasons)	Number of people

PT/OT/Speech	7
Antibiotics	2
Vent weaning	2

SRI Follow Up

Total SRI follow-up: 12 assigned

Incident Type	Number
UEIH	**6**
Neglect	**2**
Abuse	**2**
Exploitation	**1**
SPI	**1**

UEIH:

- 5/6 (83%)people that had UEIH had recommendations made at the time of discharge.
- 6 people (100%) had the recommendations completed at the time of the visit.
- 5/6 people (83%) had been discharged back to their home at the time of the visit. One person went to LTAC.
- 2/6 people (33%) 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, 1 person who was retired and 1 person went to LTAC.
- 6/6 (100%) 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

Two people received advocacy after the visit. One to ensure SSI was reinstated. We were made aware of the other person's situation when were made aware of a serious physical injury she had sustained. A look at the second situation points out the deep concerns we have when the system breaks down for individual people.

When we completed our SRI Triage on October 19, 2017 we were concerned about a person due to multiple incidents of injury/abuse/neglect over a short period of time. Specifically, the incident on that day involved a serious physical injury (swelling was noted over her eye). As we were analyzing the cumulative mosaic of the previous incidents (neglect & an unplanned hospitalization) we received a call from someone (requesting to remain anonymous) who claimed that the person was being abused by staff from her residential provider. We decided to make an unannounced visit to asses her situation. The results of that visit caused us to request

that DDS file a SRI for abuse against two staff from the residential provider. for abuse. The investigation of that incident, received on December 8, 2017 was substantiated for abuse, and the two staff in the home during our unannounced visit were terminated. The Office of The Inspector General declined to press charges.

It was our intention from the start to work in partnership with DDS senior leadership to assess the strengths and flaws of her services, with the hope that we would share a common expectation of a preferred future for her. What ensued in the more than two months required to ensure she was in a safer placement concerns us and calls into question the response of DDS executive leadership. While we did eventually work together to bring about a better outcome, we are puzzled by many of the decisions made by DDS, and the lack of urgency with which they handled her situation. Ultimately after two months of advocacy intervention, requiring our entire staff including Quality Trust's Executive Director, and the Head of DDS she has arrived at what we hope is a better future.

To go back for a minute. At the time we began working with this woman (October 2017)

Non-Medical Incidents

- Abuse-4/35 had multiple abuse incidents, 33/35 were determined to be safe, 2 people were followed up on.
- Serious Physical Injury- 7/48 people sustained their injury during a behavioral episode. 6/7 had a current BSP and 5/7 had RCRC approval. 5/7 had 1:1 staffing or higher at the time of injury. It would appear then that these interventions were not sufficient to prevent serious injury. In situations like these teams should come together to creatively consider other interventions.
- Neglect-24/75 involved medical care, 70/75 were deemed safe, and 2 people were followed up on.

Medical Incidents:

- 25/112 (22%) lived in their natural homes
- 1/112 (-1%)lived in a host home
- 47/112 (42%) lived in Supported Living
- 33/112 (29%)lived in an ICF
- 5/112 (4%)lived in Residential Habilitation
- 1/112 (-1%)lived in a nursing home
- 100/112 (89%)incidents were medical in nature and had one or more of the following diagnosis at the time of admittance.
    - 13/100 (13%)had a UTI (3%)
    - 32/100 (32%)had pneumonia (7%)
    - 52/100 had breathing problems (52%)
    - 11/100 had constipation issues (11%)
    - 19/100 had g-tube issues (19%)

    - 49/100 had seizures (49%)
    - 36/100 were vomiting (36%)
- 65/112 (58%)had no previous UEIH incidents within the last 6 months, 45/112 (45%) had between 1-3 incidents in the previous 6 months.
- 12/112 (11%) of UEIH incidents were psychiatric. 1 /12 (8%) were seen at CPSP, 10/12 (83%)had approved BSP supports in MCIS
- 7/12(58%) had 911 called

Incidents and Their Investigations

During the first quarter of FY 2018 Quality Trust received 355 Serious Reports Incidents, (SRI's), an increase of 36 incidents from the fourth quarter of 2017. The following is a breakdown of those incidents by type, and a comparison between 2017, Q4 and 2018, Q1.

Breakdown of incidents and percentages Q4 FY 2017- Q1 FY 2018

Incidents Q1 (FY 2018)	**Total Incidents**	**Percentage of total**
Unplanned Emergency Inpatient Hospitalizations	121	(34%)
Neglect	77	(22%)
Serious Physical Injury	63	(18%)
Abuse	38	(11%)
Exploitation	20	(6%)
Death	15	(4%)
Missing Person	10	(3%)
Serious Medication Error	5	(1%)
Other	6	(2%)
Total	**355**	**100%**

Incidents Q4 (FY 2017)	**Total Incidents**	**Percentage of total**
Unplanned Emergency Inpatient Hospitalizations	120	(38%)
Neglect	82	(26%)
Serious Physical Injury	43	(13%)
Abuse	37	(12%)
Exploitation	18	(6%)
Death	10	(3%)
Missing Person	5	(2%)
Serious Medication Error	2	(<1)
Other	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.

Once again unplanned hospital admissions were the highest category by count (120), which represents 38% of all incidents for the quarter. In second place, again a continuing theme is neglect. Most striking about these two charts is just how similar they are. Both is total numbers and ranking within numbers Serious Reportable Incidents have maintained consistent-Quarter 1 of last FY being the only outlier in that fewer incidents were reported.
Rather than regurgitate data from our many reports we simply refer you back to any of our previous five reports where the data are strikingly similar.
We once again request that DDS provide reporting on the content and meaning of this data. Why have unplanned hospitalizations been the most significant incident in the District since at least 2008? What explains fluctuations up and down in incidents of abuse, neglect and serious physical injury? Why have the number of deaths remained remarkably consistent given the aging of a significant proportion of the population? What explains the low level of substantiation for almost all incidents except for non-medical neglect? We have asked this question of DDS for four quarterly reports, but we have not had a response. Once again, we ask that such data analysis be completed and shared with the larger stakeholder community.