

Quality Trust Annual Report 2017 - 2018

Background

On January 6, 2017, the parties to the long-standing class action lawsuit known as *Evans v Bowser*, jointly filed a motion requesting that the court vacate all outstanding court orders in the case. At a status hearing held on January 10, 2017, Judge Ellen Huvelle officially ruled that the District of Columbia had achieved compliance in the forty-year-old litigation brought on behalf of people who resided at Forest Haven, The District's lone institution for people with intellectual and other developmental disabilities. Immediately following the hearing on January 10th, many former residents of Forest Haven, attorney's, advocates, providers and the current and former Mayor, celebrated as Judge Huvelle signed the order ending *Evans v Bowser*. With the conclusion of this court action, full responsibility for long term independent monitoring of services for people with intellectual and developmental disabilities was shifted to Quality Trust for Individuals with Disabilities.

The first resident of Forest Haven was committed on March 11, 1925. In the ninety-two years between then and now, dramatic change has occurred in the way we think about and support people with developmental disabilities. While large Institutions still exist, community-based living options are overwhelmingly the preferred approach. The funding of services for people with developmental disabilities has shifted from primarily local to federal Medicaid dollars as a significant source of financing for both community-based and institutional living arrangements. Special Master Clarence Sundrum noted in his final report that since 2000 the District of Columbia has obtained approximately 2.3 billion dollars of Medicaid funding with 1.6 billion coming from the Medicaid waiver. The waiver is known as the "home and community-based services waiver" (HCBS) because it allows states to support certain Medicaid populations in home or other community-based settings rather than in institutional or long-term care facilities such as hospitals, nursing homes or institutions for people with developmental disabilities.

The 2001 Plan for Compliance and Conclusion in the *Evans* case included among its many outcomes the creation and funding of Quality Trust. Quality Trust was intended to be a durable mechanism for safeguarding the rights and interests of people with intellectual and other developmental disabilities served by the District after the conclusion of the court action. Quality Trust is fully engaged in fulfilling our mandate to monitor and advocate for everyone receiving services through the auspices of the District of Columbia, Department of Disabilities Services. This report reflects the range of activities we undertake in pursuit of this mission.

Multi-Year Monitoring Project and Ongoing Monitoring

Prior to the completion of the *Evans* case, Quality Trust completed a statistically significant random sample of class members. The results of that monitoring were shared with the parties to the case and can be found on our website. In October of 2016, Quality Trust began a subsequent monitoring project that involved sampling a statistically significant random sample of all 2293 people receiving services and supports through the District of Columbia Developmental Disabilities Administration at that time. To attain the required level of certainty, our sample included 310 people. To further enhance the accuracy of our results, we analyzed the basic demographic characteristics of the 2293 people; looking at gender, service funding, type of living arrangements and whether the person resided at Forest Haven. This approach was designed to establish a baseline of practices in support of people receiving services and 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. By producing results that are reflective of people receiving services, we can be confident that these results accurately portray the experience of people within the system. While begun in 2016, this project took over a year to complete and was the primary individual monitoring activity during that time. The final reviews were completed in May 2018. Data were tabulated quarterly and reported to the DC Developmental Disabilities Administration throughout the duration of the project.

The final results of this project completed between October 1, 2016 until May 23, 2018 are included in this report along with additional findings and observations from the on-going monitoring we completed during Fiscal Year 2018. That includes monitoring visits we made following specific Serious Reportable Incidents (SRI), visits to people for who placement in a long-term care facility was recommended and additional monitoring triggered by Quality Trust's other monitoring and advocacy activities. We also randomly chose a sample of SRI investigations to review. This review included follow-up to see if recommendations made in the investigation based on the findings were implemented.

Monitoring:

Total number of monitoring assessments sent to DDS: 310

Total number of people who had a nursing review: 274

Methodology: Individual monitoring assessments are conducted through a combination of in-person interviews, interviews with residential and day program staff, record review, data analysis and discussions with, as needed and appropriate, the person's family, friends, advocates, DDS Support Coordinators and provider support staff. Quality Trust has developed a monitoring tool with questions that allow us to examine the care and support provided to each person and determines whether that care complies with the government requirements and professional standards. Reviewers have been trained and completed an inter-rater reliability process to ensure consistency and accuracy of case review, data collection, and analysis. Results from each review are entered into a database allowing us to aggregate and analyze data collected through our individual monitoring.

The monitoring project that produced the following results began in October 2016. It involved sampling a statistically significant random sample of the 2293 people receiving services and supports through the District of Columbia Developmental Disabilities Administration (DDA) as of that date. The sample was also analyzed based on the overall demographic characteristics of the 2293 people (e.g., looking at gender, service funding, type of living arrangements and whether the person resided at Forest Haven) to further ensure that the sample was as representative as possible of the people with disabilities within the DC DDA system.

Demographics

77% (242) waiver
22% (68) not on the waiver
16% (49) ICF/ID
45% (139) Supported Living
6% (18) Residential Habilitation
5% (17) Host Home
26% (81) Family Home
35% (107) had no day program
55% (112) Day Habilitation was the largest day program type
12% (24) were competitively employed
8% (16) were employed with help from Supported Employment
Demographically, the largest group was 51-60 years of age, 23% (72)
65% (201) were male
35% (109) were female
73% (226) walk without assistance
12% (37) used a wheelchair
46% (171) communicated using words
87% (270) reported having relationships with people other than paid staff

ISP

99% (306) had a current ISP
74% (228) required support with decision making
93% (286) had ISPs with goals that measured progress
70% (215) had an ISP with goals for work/day
53% (164) had amendments that reflected significant changes
77% (239) used adaptive equipment
86% (216) had the equipment available
99% (205) had equipment that was working
77% (239) had an IFP in the ISP

IFP

88% (180/205) had an IFP based on personal preferences
5% (9/199) were over resourced
93% (57/61) people who lived in natural homes had control over how they spent their money

Staff Training

71% (221) of residential staff had all the required trainings
80% (164/204) of day staff had all the required trainings
72% (197/274) of residential staff could describe their health-related responsibilities (not all people have staff support)
76% (155/204) of day staff could describe their health-related responsibilities (not all people have a day program)
54% (148/274) had a DSP/TME that was knowledgeable of the intended effects and the possible side effects of the medications the person receives.

Medical/Nursing Profile

7% (18) had choking precautions in place when warranted
34% (93) had bowel elimination problems
7% (18) had a communicable disease
32% (88) had a major seizure disorder
31% (85) were overweight
41% (111) had hypertension
14% (38) had diabetes
27% (126) took no psychotropic medications
26% (72) took 1 psychotropic medication
28% (78) took anti-convulsant medications for a seizure disorder
11% (30) took anti-convulsant medications for a behavioral diagnosis
88% (242) had a dental exam within the last 12 months
59% (162) had a physical examination within the last 12 months
67% (183) had a HCMP that references all their health needs
77% (212) had a nursing assessment that met professional standards as reflected by the DDS Health & Wellness Standards and the Scope and Standards of Practice for the RN and LPN

Behavioral Health

39% (121) had a restricted control for which a BSP was implemented
50% (60/121) had RCRC approval
84% (102/121) had consent for the BSP
41% (74/112) took psychotropic medications
100% of the 112 who took medications had consents in place

Service Coordination

75% (230/306) had completed the required number of monitoring tools
65% (179/276) identified concerns in the monitoring tool
59% (180) had ensured the delivery of services as outlined in the ISP

Conclusions

Throughout this project the results did not vary in any significant way from the results collected during the first quarter of FY 2017 (10/1/16 to 12/31/16). Our quarterly reports have consistently noted that in areas where performance in the service system reflects meeting standards and expectations, that success has been maintained. It has also noted that where performance was inconsistent or not strong, further improvements in practice over time were not indicated in our data.

Waiver participation at 77%, is within the margin for all quarters, and matches very nicely with data supplied by DDS. Supported Living, the least restrictive residential option available is, and has been the most popular option. DDS is acknowledged for the movement to Supported Living in community living. This option accounted for 45% of all residential options. The fact that 26% of our sample lives at home is also interesting in that it seems to indicate that the District supports a larger percentage of people outside the family home than do most other states within its formalized service system. One cautionary component of this finding is that out of home placements are necessarily more expensive than In-Home supports, so average cost per person in the HCBS waiver tend to be high. For this reason, a Living at Home waiver, much talked about but not yet developed could be a proactive approach to controlling overall waiver costs.

Here are the significant findings we found related to day programming. Thirty two percent (32%) of the people who are engaged in day programming are utilizing Day Habilitation; a service that can be highly individualized, and include significant opportunities for community integration, but which mostly occurs in "big box" locations. Day Treatment; a similar type of day programming typically associated with Intermediate Care facilities tends to be utilized by people with significant medical acuity accounted for 9%, making the combination of segregated day programming (41%). The fact that nearly half of those in the ample attend large, typically segregated day programming is disappointing. Many Day Habilitation providers in the District offer opportunities to participate in community integrated activities. However, many times the District has put a great deal of effort into a relatively new type of day programming; Individual Day Supports, IDS. As the title suggests, this service focuses on providing supports unique to each person's preferences. Ten (10%) of our sample was engaged in this type of programming. and needs. activities consist of groups (4 people or more) being transported by van to various locations in the city. Given that they travel in groups, their level of social rather than physical integration varies widely. Thirteen percent (13%) of our sample were engaging in Employment Readiness, a service designed to provide skills necessary for people who desire to work, but lack experience and skills necessary to be successful in a work environment. In our advocacy we have met people who have been receiving this service for several years but who have yet to gain and maintain meaningful employment. Employment for people with intellectual and other developmental disabilities has been a focal point of day programming alternatives in the District and nationally over the past several years. The fact that only 11% (7% competitively employed, 4% through Supported Employment) of our sample is working is disappointing and should add urgency to initiatives already underway at DDS to provide better support to people desiring to find meaningful work.

The final twenty five percent (25%) of those sampled either chose not to participate in any day program offerings, were retired or were attending community senior centers or some other non-DDS funded activity.

The fact that virtually everyone has a current ISP (99%) is a significant outcome, as is the fact that this success has been maintained for several quarters. While it's important to have a current ISP, it more important that it accurately contain all the tools necessary to provide good lives. Much of our initial work when we begin advocating and monitoring is spent pointing out the multiple errors and omissions contained in many ISPs we encounter in our day to day work. Our results found that 93% of ISPs contained measurable goals, however, many times the goals were not pertinent or particularly meaningful for the person. We believe this is an artifact of the previous approach on compliance with court orders, rather than a focus on the development of best practices in the field of developmental disabilities. Our finding that only 53% of ISPs had amendments noting significant changes is addressed within our findings regarding Service Coordination.

We developed concerns regarding the ability of provider staff to demonstrate their capabilities during our visits throughout the monitoring completed over the past three years. Evidence that the required staff training was completed for only 71% of residential staff is concerning. Documentation was located for 80% of day program staff which is only slightly better. Most concerning though is that only 72%, and 76% of residential and day program staff respectively could identify their role in carrying out the health care services and supports for the people they support. Along with this finding of concern is that only 54% of staff who administer some medications, referred to as Direct Support Professionals/Trained Medication Employee (DSP/TME), were knowledgeable of the intended effects and the possible side effects of the medications the person receives.

For DDS Service Coordination we found that 75% had completed required monitoring tools, 66% entered issues of concern in those tools and 59% had ensure the delivery of services as outlines in the ISP. Any of these findings alone is significant but taken together they describe an area of the DD system that continues to require ongoing attention for service improvement. The transformation that has launched much of the

improvement in services in the District in the last five years appears to be lagging regarding improvements needed in service coordination.

Incidents and Their Investigations

During the seven quarters covered in this report Quality Trust received 2084 Serious Reports Incidents, (SRI's). Past quarterly reports have broken incidents down by quarters and noted trends and/or patterns. The following is a discussion of incidents over the entire period covered in this report (10/1/16 to 5/23/18)

Type	Number of SRI 1306 (-128 open as of 10/8/18) = 1178	Resolved- No Neglect or Abuse Found	Substantiated	Unsubstantiated	Inconclusive	Administrative Closure	Blank- Closed with no disposition
UEIH	428 (36%)	382 (89%)	7 (2%)	2 (.4%)	8 (2%)	26 (6%)	3 (.6%)
Neglect	263 (22%)	2 (.7%)	161 (61%)	50 (19%)	15 (6%)	32 (12%)	N/A
Serious Physical Injury	203 (17%)	138 (68%)	Substantiated for neglect 16 (8%) Substantiated for abuse 3 (1%)	16 (8%)	17 (8%)	8 (4%)	3 (1%)
Abuse	136 (12%)	2 (1%)	30 (22%) Substantiated for abuse 1 (.5%) Substantiated for neglect 7 (5%)	55 (40%)	26 (19%)	15 (11%)	N/A
Exploitation	52 (4%)	N/A	15 (29%)	18 (35%)	11 (21%)	8 (15%)	N/A
Missing Person	50 (4%)	37 (74%)	Substantiated for Neglect 5 (10%)	1 (2%)	3 (6%)	4 (8%)	N/A
Death	26 (3%)	N/A	N/A	N/A	N/A	N/A	N/A
Serious Medication Error	22 (2%)	N/A	N/A	N/A	1 (3%)		N/A
Use of Approved Restraints	1	1 (100%)	N/A	N/A	N/A	N/A	N/A
Suicide Attempt	5	3 (60%)	Substantiated for neglect 1 (20%)	N/A	N/A	1 (20%)	N/A
Other	3	(67%)	N/A	N/A	N/A	1 (33%)	N/A

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 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 incidents described in the chart above represent the eleven categories tracked during all four quarters of FY 2018. The chart further delineates the percentage of the total of all incidents, as well as the disposition or findings, which are expressed in percentages of their total.

Review of the chart reveals the following. Consistent with past analysis, Unplanned Emergency Inpatient Hospitalizations (UEIH) at (36%) of incidents was the highest category of incident during Fiscal Year 18, UEIH's have been the single highest category of incident by a wide margin since Quality Trust began publishing this data. Going to the hospital in an unplanned manner is a serious and significant event. For providers, there is nothing more fundamental to their work than ensuring health & safety. Understanding the causes and trends for these incidents is important. Analyzing the role nursing supports played in a hospital admission should be one of the priorities of the QI/QA system in the District of Columbia. Since at a minimum DDS, DDA, Health & Wellness, the Department of Healthcare Finance (DHCF) or The Department of Health's, Health Regulation & Licensing Administration are involved, these efforts should be well coordinated. Regardless of the setting, (ICF/IDD or waiver) prevention of all unnecessary unplanned trips should be the goal. Quality Trust is now engaged in a rigorous study of these incidents and will produce our findings in the future.

Another significant feature of this data is their final dispositions reflected in an investigation report. Final dispositions are the work product of the DDA, Investigation Management and Enforcement Unit (IMEU). Although UEIH's are initially investigated by the provider, their investigation results are forwarded to IMEU which reviews and subsequently either accepts them or requests more information from the provider before giving final approval. In addition, certain categories of incidents such as UEIH have the potential for being substantiated for abuse or neglect. For this period, 89% of the UEIH's were resolved-without a finding of substantiated abuse or neglect. That means they were resolved (e.g. the person returned home) with no finding of neglect. It is unclear why this disposition is required for this category of incident since the investigatory question answered is whether or not the unplanned hospitalization resulted from neglect of abuse. Therefore, the circumstances surrounding the 382 people whose investigations were resolved-no abuse or neglect found were discharged with only the follow up contained in recommendations. What is unclear is the extent to which their commonalities are being analyzed for their myriad potential causes. Taken together, the dispositions indicating no neglect lead to an unplanned hospitalization (Administrative Closure, Inconclusive, Unsubstantiated, etc.,) add up to 97% of total incidents. If these results are accurate, 97% of unplanned hospitalizations were unpreventable. Quality Trust believes the issue is much more complex. It is possible that in addition to routine illness, co morbidity and uneven nursing services the current process for determining substantiation for unplanned hospitalizations needs to be examined. It is possible that more involvement from nurses from the Health & Wellness Unit of DDS is required to better analyze medical information from nurses, doctors in private practice and hospitals. All these actors are involved in many emergency unplanned hospitalizations. So, we will examine this issue in detail through our next monitoring project.

The second most frequent type of reported incident is Neglect, accounting for 263 incidents, or (22%) of all incidents. The disposition of these incidents indicates (65%) were substantiated for neglect, while (33%) were not. For Serious Physical Injury (SPI), the findings are like UEIH's in that 70%, (64%+6%) were either resolved-no abuse or neglect found, or unsubstantiated.

The 26 deaths in FY 2018 is slightly below the total from past years, where 32-35 people died each year. The rate of deaths has been relatively stable for several years at approximately 35 per year. DDA is encouraged to engage in significant planning now to address the unique services and supports of the previous residents of Forest Haven as they continue to age. Development of specialized homes that provide for optimal nursing care, while keeping community integration principals is required to prevent future over reliance on referrals to nursing homes and other long-term care facilities when health issue become more complicated. These settings do not have a strong track record of providing excellent support and care to people with intellectual and developmental disabilities.

Advocacy

There were fifty-seven (57) people supported through advocacy during Fiscal Year 18. Thirty-six (36) new referrals were received although six (6) people decided not to continue after our initial meetings to discuss their concerns. The main source of referrals for advocacy is family members. The second highest number of referrals came from outside agencies. Thirty-three (33) outcomes met were met for this group. Outcomes included: residential moves and supports, assistance with medical and nursing supports, supports for family members who were having problems with providers, technical supports with obtaining or maintaining In-Home Supports, assistance with guardianship and legal issues and accessing DDS and RSA supports. There was a decrease in referrals made by DDS Service Coordinators from earlier years. One possible reason for this is improvement by Service Coordinators in handling day to day aspects of advocacy issues that came to them. When Service Coordinators did refer a person for advocacy, it was often to have a neutral person involved in difficult situations-especially disputes between the person, their families and providers. It was noted that while overall referrals decreased, the length of time required to achieve success many times stretched into months. People who reached out to us while they were involved in the DDS application process required several months of consistent involvement to assist them through the DDS Intake process. The following vignettes illustrate some of the challenges experienced while supporting people in this process.

Mr. A

Mr. A's mother requested support from Quality Trust to assist her son (Mr. A) through the DDS Intake process. After the Quality Trust Navigator became involved with the staff from DDA's Intake Unit he was approved for services. Begun in January of 2018, our advocacy supports for this person were required for eight months to achieve this outcome.

During the lengthy intake process his need for residential placement became immediate. The advocate called and emailed the assigned DDS Service Coordinator and was presented with multiple and shifting reasons for delay. At times his eligibility for SSI/Medicaid was questioned. This required outreach to the Department of Healthcare Finance. At other times we were told that for DDS to follow their internal policies and procedures, his needs and preferences would need to be subordinated. In addition to the long hours required by the Quality Trust Navigator, intervention by the Quality Trust CEO with the acting Director of the Developmental Disability Administration (DDA) was also required to achieve success.

Another barrier was the development of a Behavior Support Plan (BSP). Mr. A experiences Autism, so supports targeted at helping him interpret the world successfully are crucial to his success living in the community. A rough draft was finalized, but staff were not trained on its implementation greatly limiting his opportunity to engage in recreational, social and vocation la opportunities. Eventually a meeting was required to make progress. Having completed this task, the last barrier was miscommunication between the provider and parent. The provider became frustrated with the level of involvement by Mr. A's mother requiring the Quality Trust Navigator to act as an outside and neutral party to facilitate effective communication.

Ann and Will

Ann and Will were referred to us by DDS. This brother and sister have been successfully navigating through the social service system in the District of Columbia for years without requiring any significant support. They had received assistance from RSA in different ways for varying degrees of support. Initially our advocacy started was targeted on assistance with the DDA application process. For these two people, providing the required information to complete the intake process was challenging. The Quality Trust Navigator had to assist them to request medical evaluations, search for school records and find any documentation of a qualifying diagnosis prior to age eighteen. Several months were required to exhaust all avenues for documentation but none could be located. In the absence of historical documents, the DDA makes their own determination based on a current psychological assessment. Ann was found ineligible, and we are awaiting the outcome of Will's assessment.

As often happens, once begun advocacy reveals other needs. In her case, Ann needs reliable access to adequate amounts of food, affordable housing, counseling services, and not surprisingly given her denial of supports from DDS more support from RSA. Quality Trust has assisted her with arranging

counseling services and assisted her with gaining access to enough food. Ann was encouraged to start utilizing other agencies including the Bread for the City Food Pantry. Strong advocacy efforts were made with RSA which led to their increased support and a current vocational assessment. However, RSA Case Management has been woefully lacking in timeliness and impact.

Will had his own personal outcomes as well. He lost his job over a year ago and RSA has been a barrier to him finding new employment. They continue to be a barrier despite strong advocacy. Quality Trust has communicated with the Program Manager for VR Services involved due to lack of response from other advocacy efforts. When Will lost his job, it caused him to have issues with his housing and he too has experienced regular access to adequate amounts of food. To help with this, Quality Trust has assisted him in applying for Social Security benefits. Once again lack of acceptable documentation of his disability caused hardship and delay. The determination process through the Department of Human Services' Income Management Agency has begun. As was the case with his sister, Quality Trust linked Will to the food pantry at Bread for the City and other churches in his community for support him until he begins receiving SSI.

Investigations:

In Fiscal Year 2018, Quality Trust followed up on one hundred forty-one (141) Serious Reportable Incident (SRI) investigation recommendations to determine if staff for whom retraining was recommended could demonstrate mastery of the skills required. One hundred seventeen (117), or (83%) involved recommendations from Unplanned Emergency Inpatient Hospitalizations (UEIH's). We found that training occurred as required for 135 of the 141 investigation recommendations, (96%). Direct observation of those Direct Support Professionals (DSP's) performing the specific duties confirmed their competency in 118 instances, (84%). The differential (96% paper vs 84% observed compliance) is in keeping with our findings in our monitoring tool regarding staff training overall. Quality Trust reviewers interviewed and observed staff as they were supporting the person being followed. They asked specific questions pertaining to the matter being investigated. If staff were unable to communicate the recommended supports or were observed not following recommendations, it was reported back to the provider.

Long Term Acute Care Placements (LTAC):

During the Fiscal Year there were twenty (20) notifications of Long Term Acute Care Placements (LTAC's) received. Two (2) people were noted to be placed in LTAC's for several years due to use of ventilators and the preference of their guardians that they remain in these placements. The reasons for placements varied, but overall the primary needs were: physical therapy services, IV antibiotic care and tracheostomy/vent care. Other needs were ventilator weaning, occupational therapy and skilled nursing services. There were two (2) instances where we observed substandard supports being provided. In both situations we noted our concerns to DDA. In one instance a plan for improvement with the LTAC provider was implemented, and in the other a residential provider stepped in to provide the required information that the facility was lacking. People in LTAC's have often previously been followed up through our SRI follow up process. The Quality Trust Navigator visits people while in an LTAC and again after they return home to ensure that all discharge recommendations are met.

SRI follow-up:

There were thirty-six (36) Serious Reportable Incident (SRI) follow up visits made during this Fiscal Year. Concerns for people experiencing an Unplanned Emergency Inpatient Hospitalization (UEIH) were the most numerous category of SRI follow up. We also become involved when circumstances surrounding abuse and neglect cause heightened concerns. Five (5) of the people followed up were referred for advocacy because their issues had been occurring for so long. The following is an example of the types of issues and concerns involved in these follow up activities.

Eden

During our usual review of Serious Reportable Incidents, a follow up was assigned due to repeated incidents for Eden. Later that same day, the day program contacted Quality Trust and asked for an advocate for Eden due to the concern that possible abuse and neglect were occurring at the residence. Eden is a woman noted to engage in Self Injurious Behavior (SIB). When we began our involvement with her, we noted that an investigation completed previously included pictures like the

wounds we observed. The open wounds were noted on her head, ears, under her eyes and her upper arms. A visit was made to Eden's home. During this visit, the Quality Trust Navigator observed two staff being verbally and physically abusive. Quality Trust notified senior DDS, DDA staff and a Serious Reportable Incident for abuse was filed against the two staff members. Once completed, the investigation substantiated abuse for both staff, who were terminated. Despite that and our findings, many of which were confirmed by DDA, Health & Wellness staff at a later visit, nearly three more months of intensive advocacy was required to ensure Eden was transferred to a new provider. Once again, the unifying theme of concern was lack of urgency and multiple differing explanations provided by DDA staff for delay. The Service Coordinator was responsive and eager to assist Eden in finding another living arrangement quickly, only to be slowed down by her supervisor's interpretations of requirements and misunderstanding of DDA policy and practice. Despite the inordinately long time required, Eden was ultimately transferred to a new provider where she is currently doing much better. Her wounds have healed considerably and continues to heal. Most importantly, she is more at ease and not fearful in her home environment anymore.

RCRC Review:

Quality Trust's reviews and analyzes the data from the meeting minutes of the Restrictive Control Review Committee ("RCRC"), which reviews behavioral support plans to ensure restrictive controls within them are appropriately justified. These minutes are generally provided by DDS on a monthly basis.

Based on that review, during the Fiscal Year 2018:

- The RCRC reviewed a total of 637 Behavioral Support Plans ("BSPs") for 497 people.
 - Most reviews were identified as non-emergency reviews of new BSPs (528; 83%) and updated BSPs (106; 17%).
 - 2 BSPs were identified as being reviewed on an emergency basis.
 - 1 BSP did not identify whether it was a new, updated, or emergency review.
- Of the BSPs reviewed:
 - 579 (91%) were approved.
 - 163 (26%) 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
 - 12 (2%) of the BSPs were rejected.
 - 45 (7%) of the BSPs were deferred.
 - 40 of the BSPs were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 required criteria listed in DDS' RCRC Procedure.² More specifically, RCRC found:
 - In 24 of these deferred cases, the BSP did not include procedures to address behavioral issues consistent with DDA policies.
 - In 17 of these deferred cases, the BSP did not include targeted behavior that was consistent with the person's diagnosis.

¹ 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."

² 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 21 of these deferred cases, there was not a rationale for using the restrictive interventions
- In 30 of these deferred cases, RCRC found that 2 or more of the required criteria were not met. Yet, RCRC still did not reject the BSP.
- 1 BSP was not approved, rejected, or deferred, because the RCRC removed it from the agenda, because they recommended it be discontinued.
- The five most common restrictive controls reviewed were the use of psychotropic medications (within 614 or 96% of the BSPs), behavioral one-to-one aides (within 234 or 37% of the BSPs), physical restraint (within 86 or 14% of the BSPs), “sharps restrictions” (within 65 or 10% of the BSPs), and individualized housing (within 34 or 5% of BSPs)..
- The RCRC reviewed 47 requests for exemption from the requirement of having a BSP. 8 of these were approved, 2 were rejected, 1 was deferred, and 1 was removed from the agenda.

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 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:

- 141 BSPs (22%) 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.³
- 104 (16%) of the BSPs were approved, even though the BSPs refer to a restrictive control that requires further justification.

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:

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 FY 2018, DDS provided us with the minutes from HRAC meetings held on October 6, 2017; October 13, 2017; October 25, 2017; November 22, 2017; December 14, 2017; December 27, 2017; January 24, 2018, January 29, 2018; February 28, 2018; March 13, 2018; March 28, 2018; April 25, 2018; May 23, 2018; June 27, 2018; June 29, 2018; July 9, 2018; July 25, 2018; August 10, 2018; August 22, 2018; and September 26, 2018.

Based on the minutes provided, the HRAC reviewed 214 human rights issues for 102 people during the fiscal year.

- 10 issues (5%) were reviewed on an emergency basis.
- 76 issues (36%) were about Long Term Acute Care (“LTAC”) placements.
- 59 issues (28%) were about nursing home placements.
- 43 issues (20%) were about out-of-state residential placements
- 21 issues (10%) were about restrictions, including those relating to door locks; access to house keys; door alarms; audio monitors; access to food and other dietary restrictions; hand mittens; abdominal binders; limiting access to sharp objects; a protocol for restitution for damaged

³ 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.”

property; and the rights to privacy, visitors, personal belongings, and purchases with personal funds.

- 15 issues (7%) were about other human rights concerns, including reviewing BSPs, BSP exemption requests, and a protocol to prevent suicide, as well as addressing alcohol addiction, refusals of one-to-one behavioral support and psychiatric services, and concerns about a substitute health care decision-maker.

Below are key recommendations for improvements to the HRAC process:

- As indicated in our prior reports this fiscal year, we continue to recommend that DDS recruit more external members to serve on HRAC. Such members could be recruited from, for example, Project ACTION!, the Developmental Disabilities Council, DDS' Communities of Practice, and family groups and networks. Our prior reports noted that the HRAC has had difficulty establishing a quorum of members required to vote to make recommendations. That difficulty resulted in at least 103 cases (48%) being reviewed and 81 cases (38%) being voted upon without a clear quorum, which is not consistent with DDS Procedure.⁴
- Over the course of the fiscal year, after raising concerns that the person involved could be served in a less-restrictive setting, HRAC approved several nursing home placements, because the guardian or substitute health care decision-maker refused to explore other options. However, guardian/substitute decision-maker consent does not mandate HRAC approval of a placement. When it comes to reviewing placements, HRAC's task under DDS Procedure is to "ensure that the person is in the least restrictive and most appropriate settings to meet his or her needs."⁵ If HRAC determines that there is "insufficient evidence that the placement . . . represent[s] the least restrictive and most appropriate placement," it must disapprove the placement,⁶ regardless of whether the guardian or substitute decision-maker consents. HRAC disapproval in such circumstances may not stop the placement from occurring, but such a determination properly identifies concerns that a human rights violation is occurring, which may warrant DDS taking formal action against the guardian or substitute health care decision-maker involved.
- In June 2018, HRAC declined to review two cases involving requests of people who have, for many years, lived in one-bedroom units supported by DDA. As a basis for declining, HRAC stated that the issue was a "fiscal issue and not a human rights issue." Fortunately, in July 2018, HRAC appeared to reverse that position by reviewing and approving the placements. This occurred after the ORA informed HRAC of DDS' purported position that "the rule is a person who has resided in individualized housing for years can remain in their unit so long as it is under the rental cap." HRAC must continue to view its jurisdiction broadly, as DDS fiscal issues regularly impact people's human rights. This is particularly true in these two cases, given DDS has not yet finalized its draft "Home and Community Based Setting Housing Choice Policy and Procedure," which would provide written and publicly available instructions for the handling of such situations, including the ways in which people can challenge DDS determinations.

We also urge HRAC to continue to make recommendations to DDS for broader systemic improvements within its service delivery system. For example, this fiscal year:

- HRAC recommended DDS "look into how the people we . . . support can receive IV infusion therapy services in their homes vs. having to go into LTAC facilities" – which is a systems improvement that is much needed.

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

⁵ Id. at Section 3.A.2.b.

⁶ Id. at Section 3.A.3.f.

- HRAC also reviewed a number of cases involving people who were living in nursing homes and LTACs because they were ventilator dependent and had tracheostomies. Ventilator dependency for more than a couple of weeks generally necessitates the performance of a tracheostomy. Based on its minutes, in April 2018, HRAC began to question whether some of those placements remained the least restrictive setting to meet the people’s needs, given “DDS now has a list of providers that can provide vent care in the residential setting.” In those cases, HRAC recommended, e.g., that the DDS Service Coordinator provide the support team with a list of possible residential placements in the community that could handle the ventilator care. However, by May 2018, the HRAC position appeared to change, with the minutes stating “we don’t have any providers who can do both vent and traech care.” As a result, in August 2018, HRAC made the systemic recommendation that “DDS should think of ways we can support individuals who are vent reliant to ensure they continue to have the best quality of life possible based on the HCBS settings rules, despite their placement.” We would recommend strengthening that systemic recommendation and urge DDS to explore ways in which people with long-term complex medical needs, such as the need for ventilator and tracheostomy care, can be served in less restrictive placements within the DC community.

Legal Advocacy Highlights

Quality Trust’s Legal Advocacy and Education Program provides legal services to people with developmental disabilities and their families on issues involving capacity, consent, alternatives to guardianship, and the right to self-determination; community integration; living life free from abuse and neglect; and accessing public benefits and services. In addition, our Jenny Hatch Justice Project is funded by the D.C. Bar Foundation (DCBF) to assist low-income District residents with disabilities facing overbroad or undue guardianship. We provide education, training, and support to the community on topics including supported decision-making and other alternatives to guardianship, education, school-to-adult transition planning, employment, and public benefits. We also work on systemic issues, including legislative and administrative reform, to promote decision-making and other rights of people with disabilities. Below are highlights of our DC legal work from October 1, 2018 through September 30, 2018.

LEGAL ADVOCACY AND EDUCATION

The QT Legal Department provided legal services in over 475 matters impacting DC residents with disabilities. Case highlights include:

- Representing a person with an intellectual disability in the termination of a professional guardianship in favor of a less-restrictive alternative that could be accomplished with the support of family members.
- Representing a senior in what became the first case in the District of Columbia to terminate a guardianship of an older adult in favor of Supported Decision-Making, thanks to our Jenny Hatch Justice Project. The case was highlighted by the Washington Post. For the press release, please visit: <https://www.dcqualitytrust.org/victory-in-advancing-the-right-to-make-choices/>

The QT Legal Department conducted at least 14 presentations and trainings in DC on issues involving guardianship and alternatives to over 250 attendees under our DCBF-funded Jenny Hatch Justice Project. Audiences included people with disabilities, family members, supporters, and professionals.

SYSTEMIC INITIATIVES

The QT legal department engages in systemic initiatives, including legislative and administrative reform, through a combination of coalition, committee, and local and national work. Highlights of such work include:

- Leading a coalition of local disability rights advocates and organizations in educating the public and lawmakers about DC Bill 22-0154, now known as the Disability Services Reform Amendment Act of 2017. This bill, which became official law on May 9, 2018, moved the District forward in respecting the rights and dignity of all of its residents by reforming civil commitment for people with intellectual disabilities, recognizing supported decision-making across the lifespan, and requiring DDS to create a

formal complaint process that people receiving DDA services can use to get their problems addressed. For the press release, please visit: <https://www.dcqualitytrust.org/2018dclaw/>.

- Participating in executive and judicial efforts to implement the new Disability Services Reform Amendment Act. This included working with the D.C. Superior Court to develop court templates and protocols for addressing the changes to the civil commitment law and planning to serve on a panel for a court-sponsored training for attorneys on the reforms, which occurred on June 1, 2018. This also included collaborating with DDS to develop a D.C. Supported Decision-Making Agreement Information and Instructions to accompany the form established by law and commenting on draft regulations for implementation of the formal DDS complaint process.
- Participating in the efforts of the DC Special Education Advocacy Coalition, which promotes policies and programs that increase the success of children with disabilities in school. Highlights of this work includes:
 - Participating in the coalition's successful campaign to fully fund important District's special education reforms (see, e.g., <https://www.dcqualitytrust.org/the-importance-of-keeping-promises/>). As a result, the D.C. Council allocated \$4.3 million to ensure that:
 - Schools will begin to plan for the child's path to graduation and future success at the end of middle school, and the Rehabilitation Services Administration can use Pre-Employment Transition Services funding already given to DC via the Workforce Innovation and Opportunity Act to help fourteen and fifteen-year-old students, rather than waiting until they are sixteen to provide these critical services;
 - Students receive eligibility and assistance in two months rather than almost half the school year, which will help classrooms, teachers, and the child;
 - Strong Start/DC Early Intervention Program services help more young children with disabilities catch up before they get to school.
 - Submitting testimony in support of the Student Fair Access to School Act of 2017 (DC Bill 22-0594). This bill limits the use of out-of-school suspension for DC students and creates safeguards for students with disabilities who have been disproportionately affected by existing school disciplinary policies. The legislation was enacted in July 2018 and became effective in August 2018.
- Participating in the DDS' HCBS Advisory Committee and reviewing and commenting on policies, procedures, regulations, and Waiver-related documents to further the interests of DC residents with intellectual and developmental disabilities. Highlights include:
 - Review and commenting on IDD Home and Community Based Services (HCBS) Comprehensive Waiver Renewal Application, when was approved and went into effect in November 2017, as well as its implementing regulations.
 - Providing input into DDS' plans to introduce self-direction into the IDD HCBS Comprehensive Waiver and create an IDD Individual and Family Support Waiver, both of which are anticipated to occur in October 2019.
- Serving as Project Director under a cooperative agreement with the National Council on Disability that resulted in its seminal report, "Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination for People with Disabilities," which was published in March 2018 and provides a comprehensive review of adult guardianship and alternatives through the lens of civil rights reforms impacting people with disabilities and includes recommendations for reform. For the report, please visit: <https://www.ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>.
- Serving as Project Director of the National Resource Center for Supported Decision-Making, which advances "The Right to Make Choices" of people with disabilities and older adults. The National Resource Center is funded by the federal Administration for Community Living. For more information, please visit: www.SupportedDecisionMaking.org. For more information on the impact of the National Resource Center in DC, please visit: www.SupportedDecisionMaking.org/state-review/district-columbia.

Final thoughts and next steps

It has been a little less than two years since the District exited the Evans case. The results of the compliance measuring tool we used for the monitoring described in this report are positive. Compliance with basic measures of service provision reflect the minimum required expectations, not the elements of excellent services and supports. Robust utilization of the HCBS waiver for least restrictive living options, ensuing everyone has an up to date ISP and people reporting they have people in their lives other than paid staff as friends are all very encouraging trends. However, continuously increasing the quality of supports and services is the substantial work of government agencies and providers. When some of the data in this report is viewed in that context it is clear that additional investments are needed in the District to bring the system into alignment with 21st century expectations for quality in services. Disappointing findings such as those involving opportunities to engage in meaningful work stand out. The Centers for Medicare & Medicaid Services (CMS) has imposed stricter expectations in this and other areas in the HCBS waiver.

Even more fundamental are some of our findings related to staff training, RCRC approval of Behavior Support Plans, Service Coordinators engaging in timely follow up and monitoring. These findings speak to core competencies that must be mastered to protect the health and safety of people receiving services and supports. From our experience monitoring and advocating for people with disabilities in the District over the past sixteen years the nexus of so much of what does or does not happen for people living in congregate living arrangements revolves around the core competencies of those closest to them. Taken together with the fact that unplanned trips to the hospital are the most common Serious Reportable Incident, we have chosen to examine these incidents in detail.

Each person supported is required to have a Health Care Management Plan (HCMP) completed each year as part of their ISP. Whenever significant changes to their health occurs such as an unplanned hospitalization the plan is to be updated to reflect those changes, and their Direct Support Professionals (DSP's) should receive training on the updated plan. As our findings in that area indicate, improvement is needed in that area. In the coming months we will examine the causes of unplanned hospitalizations. We will look at the role nursing services and day to day supports play in these hospitalizations. In addition, we will be examining the investigation of unplanned hospitalizations, and the recommendations contained in them. Finally, we will analyze trends in these incidents to determine if patterns are evident. To the extent we find trends, we will evaluate whether the Health & Wellness Standards currently in use need to be modified to better ensure the health and safety of the people receiving services and supports in the District of Columbia.