

## **Fiscal Year 2016 Post Compliance Monitoring Final Results and Report**

**October 2016**

### **INTRODUCTION**

This report contains results of monitoring and advocacy activities completed by Quality Trust during Fiscal Year 2016. The report is organized into the following sections:

- Individual Monitoring Results (data from review of 177 class members)
- Review and Analysis of Incidents and investigations
- Advocacy
- Involvement in DDS committees and stakeholder groups
- Presentations and Training Activities

The data included in this report were collected during Fiscal Year 2016. Activities were implemented as outlined in the plan we developed and filed with the Court in May of 2015. In addition to our on-going activities to monitor services, we completed individual monitoring for 177 class members. Our results reflect that the Department on Disability Services (DDS), specifically the Developmental Disabilities Administration (DDA) is meeting the obligations agreed upon in the 2010 update of the 2001 Settlement Agreement as measured by the questions in our tool. During this same period, we also discovered instances through other monitoring and advocacy where services to individual people failed to be provided as planned or as timely or effectively as required. These activities involved review of services for non-class members as well as Evans class members. For some people, these failures resulted in deeply concerning consequences. All of these situations were reported to DDS when found. When made aware, leadership within DDA quickly and transparently responded to our concerns. In recognition of the fact that services and systems can fail people, the goal of quality assurance activities in the District of Columbia must be to reduce and minimize service failures over time. It is therefore a shared objective that the DDS continue to evolve beyond the current compliance phase. DDS has endorsed the challenge to continue to innovate and further develop its systems for promoting continuous quality assurance. Strengthening the capacity of providers to deliver services that meet the diverse needs of the people within the DDA system should be the cornerstone of all such efforts. So while it is a notable achievement that we found every person in the sample had a current ISP, this alone is not enough to ensure people lead safe and personally meaningful lives. It is critical that those ISP's direct impactful outcomes for each person and that service providers demonstrate the capacity to competently and consistently implement those outcomes.

Our results from the review of 177 Evans class members reflect improvements remain strong since 2010 in the following areas:

- People have current ISPs
- People are receiving their Personal Needs Allowance
- Serious Reportable Incident investigations are completed thoroughly and timely
- A significant majority of people are receiving their services through the HCBS Medicaid waiver
- Supportive Living, the least restrictive model, is the most utilized residential service
- Service Coordinators are trained, maintain caseloads of 30 people or less and respond quickly when people are hospitalized or referred to LTAC facilities
- People who need assistance with decision making have assistance

Our data from all monitoring activities indicates work is needed to further improve practices in the following areas:

- Ensure that everyone supported has a current HCMP that reflects all of their healthcare needs, and that staff are trained on changes to the plan
- Nurses proactively intervene to prevent unnecessary dehydration, constipation, UTI & respiratory issues in people who require maximum staff assistance with ADL's
- DSP's receive the training required by DDS policy, and can demonstrate competency

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*This report is dedicated to the memory of William “Marty” Clark who died on May 29, 2016. Marty was a longtime colleague and valued member of our team. The parent of a daughter with developmental disability, our work was not simply his job - it was his passion. Marty is sorely missed, and his memory and presence will live on in the legacy he left behind in the hearts and minds of the people who knew him.*

### **METHODOLOGY**

The sample for individual monitoring was focused exclusively on Evans class members this year. Using a complete list of Evans class member’s provider by the Deputy Director of the Developmental Disabilities Administration, a sample of 177 people was drawn. This number was agreed upon by the parties to be statistically significant for the purpose of our simple random sample. Utilizing the same method we have used in recent years, a random integer set was utilized, and a list of individual class members was chosen. We set our confidence interval at 5%, meaning that the percentages contained in this final data can be thought of as reflective of the entire class within 5%. We began the individual review work in October of 2015 and have been submitting quarterly reports on our findings as laid out in our Monitoring Plan submitted to the court in May of 2015.

### **THE INFORMATION IN THIS SECTION INVOLVES EVANS CLASS MEMBERS ONLY**

#### Monitoring

#### Random Sample of 177 class members-Data Summary

Below is a summary of selected highlights from the people we met and overall data collected throughout FY 2016. Detailed results for all of our FY 2016 monitoring are attached to this report.

#### Demographics:

- 120 people (68%) were supported through the HCBS waiver
- 57 people (32%) live in ICF’s/IDD
- Of those people supported through the waiver, 83 people (69%) live in Supported Living arrangements; the least restrictive option available in the District
- 112 Men (63%) were reviewed
- 65 Women (37%) were reviewed
- 83 people (47%) were between the ages of 51-60
- 67 people (38%) were between 61-70
- These 150 people between 51 and 70 years of age made up (85%) of the sample
- 53% (93) people required no assistance while walking
- 24% (43) people required some type of assistance while walking
- 23% (41%) People use a wheelchair

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- 148 people (84%) participated in some type of day program activity
- 89 people (60%) participated in Day Habilitation\*
- 36 people (24%) participated in Day Treatment\*
- 38 people (26%) participated in Individualized Day Services (IDS)\*
- 29 people (20%) did not participate in a formal day program activity\*
- Please note that the above numbers equal more than 100% because people participate in more than one service.

### ISP:

- ALL 177 people (100%) of the people reviewed had a current ISP
- 157 (89%) of the people we met were deemed to need assistance with decision-making
- Of that total 152 (97%) had the recommended assistance
- 170 people (96%) of the ISP's had goals and outcomes which reflected the person's preferences and needs
- 166 ISP's (94%) had measureable criteria to determine if progress was being made
- 164 (93%) of the people had at least one piece of adaptive equipment.
- 140 of those people (85%) had the equipment, and it was in working order
- 129 people's adaptive equipment (79%) was in being used correctly

### Personal Possessions

- 170 of 177 people (96%) had an IFP in their ISP
- 159 of 167 people (95%) had financial information available (10 people managed their own funds)
- 162 of 167 people (97%) were receiving their personal needs allowance

### Staff Training (Combined residential & day program)

- In their homes, we found evidence of required training for DSP's for 130 of 175 people (74%), at the day program the number was 108 of 148 people (73%). Two people were living on their own without any type of support staff
- In the homes, staff for 162 of 175 people (92%) could describe the person's preferences and needs, while at day program (85%) could describe the preferences and needs.
- At homes, DSP's could describe their responsibilities for carrying out the person's HCMP for 124 of 169 people who had a HCMP (73%), while at the day program staff for 96 of 120 people (80%) who had tasks contained in the HCMP could identify those tasks

### Nursing

- 175 of 177 people (99%) had a current physical examination
- 164 of 174 people or (94%) had evidence of follow up on recommendations from their physicals
- 170 of 176 people (95%) had a current dental or a variance if appropriate
- 125 of 131 (95%) had evidence of recommendations from medical specialists being implemented in a timely manner
- 132 of 172 people (77%) had a HCMP that referenced all of their health needs
- 124 of 157 (79%) HCMPs were updated according to DDS, Health and Wellness (H & W) Standards within the required timeframe of identification of a new health concern

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- We found evidence that the HCMP was updated to reflect changes in health for 124 of 158 (84%) people
- Staff for 134 of 168 people (80%) had been trained on the updated plan
- 84% of the nursing assessments (162 of 173) met professional standards
- 83% of RN notes indicate they are coordinating healthcare services, (143 of 172)

### Behavioral Healthcare (combined residential & day program)

- 72 people (41%) had a restricted control implemented for which a BSP is required
  - Of those, 66 people or (92%) had evidence of consent or an approved opt out
- 57% of people for whom RCRC approval of the plan was required had evidence that the BSP's had been reviewed and/or approved by DDS
- 92% BSP's were being reviewed quarterly by a Psychiatrist
- 85% of people supported by a BSP were being monitored for Tardive Dyskinesia
- 79% of the BSP's were being implemented at both the home and the day program

### Day/Vocational Program

- 141 of the 177 people (80%) had some type of planned day activity
- 141 of the 148 people (94%) had a current ISP at their day or vocational program
- Staff at the program was collecting data toward the goals and outcomes for 129 of the 148 people or (87%)

### Service Coordination

- 92% of Service Coordinators had a caseload of 30 people
- 92% of Service Coordinators had all required training
- 93% of Service Coordinators had documentation that they made all required visits
- 94% of Service Coordinators could identify the preferences of the people they support
- 92% of Service Coordinators were able to identify the person's health needs
- 90% of Service Coordinators were ensuring delivery of the services outlines in the ISP

## **THE INFORMATION IN THIS SECTION OF THE REPORT INVOLVES CLASS AND NON CLASS MEMBERS**

### **Incidents & Investigations**

#### Incidents

Quality Trust received 1249 Serious Reportable Incidents from DDS in FY 2016. Compared to the 1128 we received during FY 2015, this is a 9% increase. Of the 1249 incidents, 449 (36%) involved unplanned hospitalizations. This is the first reduction from recent years where the percentage of total incidents has remained between 40-43%. Last year for instance they were 464 of 1128, or (41%). Of the 449 incidents in FY 2016, 206 (47%) were single occurrences. This means that the person did not experience any

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other incidents of any kind in the six months prior. We also found that 164 people had between 1-3 incidents prior, and 50 people had 4-6, or close to one per month. Seven (7) people accounted for more than seven incidents each. Further analysis revealed that three (3) people accounted for 33 UEIH's, all of which involved psychiatric admissions. We also found through our triage process for these incidents that 97% of the time Service Coordinators were notified of the incident, and 88% of the time they followed up within two business days as required by policy. However, the required monitoring tools had been completed only 69% of the time. The DDA Health & Wellness unit was involved with 74% of people who had multiple hospitalizations. It is important to note that these indicators do not necessarily link or explain the reduction. As mentioned in previous quarterly reports, the Quality Improvement Committee (QIC) has identified this issue as one to be thoroughly examined as part of its charge. Researchers through the Georgetown Health Partnership made a presentation to the committee in June and presented additional data in July. The information raised a number of new questions regarding both methodology and findings. The QIC is still waiting for the Georgetown researchers to provide clarification on their initial research and presentation findings. We have requested that this item be on the agenda for each of the meetings since July. We will continue to pursue this issue until the data needed is presented and committee members are comfortable moving forward with its analysis.

The second largest category of incidents was neglect at 261 (21%). Neglect has been the second largest category since 2011, when including neglect as a causal factor in unplanned hospitalizations was first implemented.

There were 191 (15%) incidents reported involving serious physical injuries. This is the third largest category of incidents. The increase from 49 incidents in FY 2015 to 191 in FY 2016 is a significant change. This was presented as a concern at the June QIC meeting. Follow-up by DDS revealed that the Incident Management Enforcement Unit (IMEU) had audited serious physical injuries in the first quarter of FY 2016 and found that many were misclassified as physical injuries - a less serious Reportable Incident - because a "medical professional" said the injuries did not produce lasting concerns. After the audit, DDS made a change in practice which resulted in the increased number of incidents. We conducted an internal review and found similarly that the majority of reported incidents involved low level injuries and that 82% were unsubstantiated for neglect as a causal factor for the injury.

Allegations of abuse accounted for 170 (14%). Once again, allegations of abuse have remained in this fourth position for several years now.

Together the four categories of unplanned hospitalization, neglect, abuse, and serious physical injury accounted for 1116 (89%) of the 1249 Serious Reportable Incidents reported in the fiscal year. These findings are consistent with the past several years, with the 4 - 5% reduction in unplanned trips to the hospital noted.

The annual number of deaths in the DDS DDA system has remained relatively stable for the past several years. For example, there were 35 deaths in FY 2016 compared with 34 in FY 2015. When looking at deaths for class members specifically, we note there were 18 class member deaths in FY 2015, and 17 in

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FY 2016. Of the total deaths in FY 2016, we found that 11 of the 35 deaths (31%) involved two residential providers.

As part of our focused healthcare review process, we are completing in-depth reviews of each of these 11 deaths. Our method for this work is straightforward: we are reviewing nursing notes and other documentation from the residential provider, the Columbus mortality investigation reports, the progress notes and monitoring tools completed by the DDA Service Coordinator, and the minutes of the Mortality Review Committee (MRC) meetings at which the deaths are discussed. Our objective is to determine if the current array of DDS interventions and oversight is functioning optimally to reduce the likelihood that mistakes or failures associated with the person's care are repeated. We recognize that every death is the result of circumstances and characteristics unique to the person. At the same time, problems within providers likely require interventions centered in the culture and practices at that agency. In addition, if similar failures are noted across providers, systemic interventions by DDA are required.

Once our in-depth reviews of these 11 deaths are completed, we will release a separate report with our findings. However, based on the work we have done so far, we have the following observations:

- It appears that current DDS policy and practice are generating sufficiently rigorous reviews of each death at an individual level. For example, our review thus far confirms that 5 of the 11 deaths have been reviewed by the Columbus Organization and that the MRC has reviewed the recommendations for four (4) of the five (5) deaths. In completing that review, MRC approved, modified, rejected, and/or made additions to the Columbus Organization's recommendations, after deliberation and discussion
- It is not clear the extent to which DDS tracks repeatedly identified issues within or across providers to prevent and/or mitigate such issues in the future. We will request more information from DDS as to whether and/or how its various units track and share trending recommendations from MRC and Columbus; the data from IMEU investigations, findings from DDA Service Coordinator's monitoring tools, and the results from provider readiness certifications (PRC)
- We noted in multiple Columbus investigations that charting errors, communication breakdowns, and failures in supervision by RNs were concerns for which retraining of both DSPs and nursing staff was recommended. To address these kinds of on-going concerns, we would expect DDS to provide MRC with the kind of trending analysis described above so that it can be supported in making provider-wide and/or systemic recommendations. To our knowledge, DDS is not currently sharing such trending and analysis with MRC on a regular basis
- The most recent death investigation received revealed multiple failures by the RN, LPN and DSPs and concluded that the death was unexpected and preventable. While the MRC has not yet met to review the death, we urge DDS to take swift and necessary remedial actions so that disciplinary measures and/or sanctions are imposed as warranted and protections are in place for other people supported by these same staff

More detailed individual and systemic findings and recommendations from this focused health care review will be included in the final report.

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Of the 1249 incidents reports received, 331 (26%) involved class members. This is a proportional share of overall incidents as the class now accounts for approximately 20% of all people receiving services. Unplanned hospitalizations accounted for 42% (138) of all incidents involving class members. This is a significant increase compared to last year's percentage of 28% (130 of 464). As class members age it is natural to assume that hospitalizations may be an increasing share of their total incidents, however without more data on the specific nature of these hospitalizations it is premature to draw firm conclusions. Once again, the research from Georgetown is critical to achieving a better understanding of the increased frequency of class member's use of emergency rooms in accessing healthcare.

### Investigations

We completed 141 investigation follow ups in FY 2016. The focus of this work was to determine if staff for whom retraining was recommended could demonstrate they had mastered the skills required. This work began in January 2016 while several of our staff were participating in the final round of joint monitoring for the *Evans* case.

The results of our review of investigation recommendations are summarized below. Of the 141, 83% involved Unplanned Emergency Inpatient Hospitalizations.

- 51% involved class members
- 84% occurred in the person's home
- 9% were at day program
- 7% were in the community
- 49% of the dates for provider POC completion in MCIS were in agreement with the PDF copy
- 67% contained at least one recommendation involving retraining
- Of those investigations involving a recommendation for retraining we were able to verify 96% had documentation of the required retraining
- Upon direct observation we were able to verify DSP's competency in 84% of our observations

As evidenced in the bullets above, overall we found that training occurred as required 96% of the time. However, we also encountered instances where it did not. One example of follow-up on required retraining and replacement of adaptive equipment found that the required equipment was not in the home and the DSP could not explain its proper use. This instance resulted in two issues to be addressed. We notified the leadership of DDS of this serious deficiency, and a Serious Reportable Incident was filed. That SRI was investigated and substantiated for neglect as far as the lack of retraining. In another situation we encountered a provider who was appealing a finding of substantiated neglect, who when we asked to review documents refused to allow us to do so. We also found several other issues, including Service Coordinator monitoring tools which were not uncovering instances of the provider failing to ensure the person had the services as planned. We brought this concern to the Deputy Director of DDA, who acted to sanction the provider and required quick follow-up on outstanding issues. These types of situations were encountered throughout the year, and when we brought issues forward, DDS leadership was quick to address the issues and respond to us with the results of their interventions. It is worth noting here that these types of issues reinforce the need for quality assurance systems that can identify and

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quickly resolve problems proactively. This type of continuous quality assurance is precisely where DDS will need to concentrate as they move forward beyond the *Evans* case.

### Admissions to LTAC Facilities

We received notice of 42 proposed placements in long term acute care facilities during FY 2016. Two people have remained in long term care placements for several years due to use of ventilators and family/guardian preferences. One of those people lives in New York and according to our review of the Service Coordinator's progress notes, is being followed on a monthly basis. We have concerns about the other person. Despite numerous meetings between DDS staff at all levels and her guardian, the guardian refuses to consider removing her from a ventilator. Several physicians and legal representatives have weighed in that it is virtually impossible to expect this person to progress beyond her current level of ventilator dependency. Despite that information the guardian insists that her current status is providing the person with a good quality of life. We have initiated advocacy for this person. Two people experienced extended placements due to preferences by their decision makers for them to stay in these placements rather than return to community based living arrangements. Through Quality Trust advocacy one person moved to a Supported Living arrangement in September of 2016. A transition to an ICF/IDD for the second person is scheduled for the near future.

Our monitoring of activity over the past year indicates that DDS is meeting its requirements in this area by: making proper notification of proposed placements, sending Service Coordinators or clinical staff to follow people once placed, holding discharge meetings, and completing monitoring when the person returns home.

There were two instances of concern identified this past year related to long term placements. We identified one LTAC that was providing substandard supports to people placed in their facility through our follow-up. DDS was also concerned about this facility and made several visits to assess the situation, discussed their concerns with senior leadership of the facility and developed a mutually agreed upon improvement plan. In another instance, a hospital (Georgetown) discharged someone without the participation of the Service Coordinator or residential provider. The QT monitor visited the LTAC provider on the day the person arrived and confirmed that no information accompanied him. The monitor contacted both the Service Coordinator and the residential provider. A representative from the residential provider then made a visit and provided the necessary information.

The following list is a breakdown of the types of specialized care required in an LTAC setting:

- Four (4) people needed assistance with or time in the facility due to tracheotomy/ventilator use
- Nine (9) people required extended IV Antibiotic therapy
- One (1) person required post-surgical Rehabilitation
- Fourteen (14) people participated in extended PT/OT therapies
- Five (5) people had extensive wound care follow up services
- One (1) person required various therapies post heart attack:
- Three (3) people were placed after hospitalizations for respiratory failure:



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- Three (3) people required G tube follow up support
- One (1) person had specialized chest tube care
- One (1) person required skilled nursing supports

We also received notices of proposed placements for four (4) people who did not end up requiring them and for whom the placement was never made. The following is also noted:

- Seven (7) people died within 60 days of the placements
- Four (4) people had more than one placement

A total of twelve (12) people who had an LTAC admission also had issues which caused us concern, so we provided continued our involvement after the LTAC placement ended. The main reasons for our continued supports were:

- Failure of the residential provider or DDS Service Coordinator to ensure timely and/or consistent transition services;
- Failure to follow up on discharge recommendations in a thorough or timely manner.

### **Advocacy**

The chart below indicates the volume and type of requests for advocacy we received in FY 2016. The reasons for our advocacy support are as varied as are the sources of formal requests. The length of our involvement also varies, but our goal is to achieve outcomes within 90 days. In many cases we find that no more than 30 days is required to achieve the desired outcomes. Through our strategy of bringing the key players together, we are frequently able to identify and overcome barriers. When necessary or resolution is not possible, we elevate the problem to the highest levels for intervention and/or more timely resolution.

- 35 New referrals (42 referrals in FY15)
- 35 people closed, 24 outcomes met
- 11 closed with no outcome (people changed their mind, were unresponsive or without supporting documentation).
- Currently, 10 people have been carried over into the next fiscal year. In FY 2015 ten people were carried over into FY 16

Referral Source	FY 2016 # of referrals	FY 2015 # of referral s
DDS	1	4
The person	2	4
The person's family or friends	20	14
APS	1	0
Guardian	1	0
Attorney	1 (QT attorney)	1 (QT attorney)
Outside Agency	4	12
Provider	3	2
QT Monitor	1	4

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Georgetown	1	1
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**Number of outcomes**

<b>Outcome</b>	<b>Number of outcomes</b>
Family/provider communication	4
Residential move	3
In home supports added	1
Day Program change	2
RSA application	1
Adaptive Equipment	1
Medical Supports	4
Court appointed advocate put in place	1
Food purchased and grocery schedule worked out	1
Speech, dental, nutrition etc. put into place	1
BSP put into place	1
Vacation funded	1
Access to DDS	1
Monitored for problems at families request	1
SSI started	1

**People referred within the QT**

<b>Referred to</b>	<b>Desired Outcome</b>
Resource Specialist	Section 8 housing
Resource Specialist	Children's therapies
Legal	Guardianship
Legal	RSA appeal (external referral)

Quality Trust's advocacy efforts have continued this year with very similar overall numbers as last year. We received 35 new referrals this year compared to 42 in FY 2015.

57% (20) of the referrals came from family or friends of the person, which is an increase from 24% last year. Of the 42 referrals last year, 14 (33%) came from family or friends.

There was also a change in the number of referrals from outside agencies. This year they referred (11%) (4/35), while last year that total was 12/42 or (29%). This year outside agencies included; Adult Protective Services, Georgia Avenue Family Collaborative, DC Safe and MBA Non Profit Solutions.

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There was a decrease in referrals from DDS Service Coordinators. In FY 2015 (10%) of our referrals came from DDS, and this year there was only 1. From a historical perspective, this appears to demonstrate the marked improvement of Service Coordinators to handle many of the day to day aspects of advocacy issues that come to them. When QT began offering services in 2003, we received many referrals for Service Coordinators or families of people receiving services requesting very basic lay advocacy or case management tasks.

Our largest categories of outcomes were medical supports and supporting family/provider communication. They accounted for 48% of the outcomes met with 4/24 each. After that there were 3 residential moves and 2 day program changes.

11 people changed their minds or were unresponsive about going forward with advocacy once started. Reasons cited were processes being too long and complicated, a person not having a green card and therefore unable to receive services, people changing their minds, one person refused supports initially and one person was referred to Adult Protective Services.

### **RCRC Review:**

Quality Trust's legal team reviews and analyzes the data from the meeting minutes of the Restrictive Control Review Committee ("RCRC"). These minutes are provided by DDS on a monthly basis.

Based on that review, during the entirety of FY 2016:

- The RCRC reviewed a total of 685 Behavioral Support Plans ("BSPs") for 547 people.
  - The majority of reviews was non-emergency reviews of new BSPs (574; 84%) and updated BSPs (37, 17%)
  - 21 BSPs (3%) were reviewed on an emergency basis, and 3 BSPs (less than 1%) were emergency re-reviews or follow-ups.
  - 8 BSPs (less than 1%) were not specifically identified in the minutes as new or updated (7, 3%).
- Of the BSPs reviewed, 610 (89%) were approved, 5 (1%) were approved for 2 years, 4 (1%) were approved for 90 days, 5 (1%) were approved for 60 days, 1 (less than 1%) was approved for 45 days, and 2 (less than 1%) were approved "once revisions [were] made."
  - 209 BSPs (31%) were approved even though the RCRC minutes included substantive comments requiring the revision of the BSP, requesting additional information or justification for the restriction, and/or raising issues that called into question whether the BSP met the 8 criteria listed in DDS' RCRC Procedure.<sup>1</sup>
    - In the last half of the year alone, 92 BSPs (24%) 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.
  - 5 BSPs were approved without the RCRC minutes including answers to the 8 required criteria listed in Section 3(D) (3) of DDS' RCRC Procedure.

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<sup>1</sup> Procedure No. 2013-DDA-PR014.

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- 1 BSP was approved even though the RCRC concluded the BSP did not meet 3 of the 8 required criteria listed in the DDS' RCRC Procedure.
- 18 (3%) of the BSPs were rejected.
- 39 (6%) of the BSPs were deferred.
  - 33 BSPs (5%) were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 criteria listed in DDS' RCRC Procedure.
- 1 BSP was not approved, rejected, or deferred, because it was identified as a non-restrictive plan that did not require RCRC review.
- Of the BSPs reviewed:
  - 677 (99%) included requests for the use of psychotropic medication;
  - 211 (31%) included requests for the use of behavioral one-to-one aides;<sup>2</sup>
  - 56 (8%) included requests for the use of physical restraint;
  - 32 (5%) included requests for the use of sharps restrictions;
  - 29 (4%) included requests for individualized housing or individualized housing with de facto one-to-one support or 24/7 staffing;
  - 27 (4%) included requests for the use of behavioral two-to-one aides;
  - 19 (3%) included requests for the use of medical sedation;
  - 16 (2%) included requests for the use of protective/safety helmets or cloth head wrappings
  - 8 (1%) included requests for the use of door alarms, chimes, or buzzers; window alarms; or arm alarms "for medical purposes";
  - 8 (1%) included requests for the use of other environmental modifications;
  - 8 (1%) included requests for the use of protective mittens, geri sleeves, wrist guards, and long sleeve shirts to prevent skin picking;
  - 6 (1%) included requests for the use of grocery storage protocols; locked cabinets, "personal clothing/belongings locked away," or "safety locks for food and transportation";
  - 5 (1%) included requests for the use of environmental sweeps;
  - 4 (1%) included requests for the use of cell phone or phone/internet restrictions;
  - 4 (1%) included requests for the use of smoking protocols or restrictions;
  - 3 included requests for the use of restrictions relating to aerosols, cleaning supplies, matches, lights, or chemicals;
  - 3 included requests for the use of search protocols or room or closet searches;
  - 2 included requests for the use of monitoring for smoking hazards;
  - 2 included requests for the use of gait belt<sup>3</sup>;
  - 2 included requests for the use of an incentive plan;
  - 1 included a request for the use of a behavioral three-to-one aides for 90 days only;
  - 1 included a request to restrict visitation;
  - 1 included a request to remove locks and the bedroom door; and
  - 1 included a request for the use of safety checks.

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<sup>2</sup> Note that 31 BSP reviews included reference to medical one-to-one aides. Per DDS Procedure No. 2013-DDA-PR08, such requests are generally reviewed by the DDA Health and Wellness Unit, rather than the RCRC.

<sup>3</sup> The review of the gait belt may have been reserved for review by the DDA Health and Wellness Unit.

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- The RCRC reviewed 27 requests for exemption from the requirement of having a BSP. All were approved.

Over the course of this fiscal year, we have seen improvements made to the RCRC processes, as reflected in its minutes and in response to the recommendations made in our quarterly reports. For example, in the third quarter, the RCRC began using a “Yes, with recommendations” designation, when it determines a BSP meets the 8 criteria in the DDS RCRC Procedure, but has further recommendations for improvements that should be made to the BSP. The DDS Rights and Advocacy Specialists (RAS) also changed the RCRC review template, among other things, to clearly identify the living arrangement that a person is in (e.g., Supported Living, Residential Habilitation, Intermediate Care Facility, etc.), so the RCRC includes that factor in its analysis as to whether a restrictive control, such as a behavioral one-to-one aide, is justified.

In addition, beginning in the third quarter, the RCRC minutes began to expressly include answers to the list of criteria required to be met for BSP exemption requests to be granted under Section 6(D) of the DDS BSP Policy. However, there was a backslide in that regard in the fourth quarter, during which answers to the exemption criteria were recorded in the minutes for only half of the exemption requests RCRC reviewed. Therefore, we ask that DDS direct the RAS to consistently record those answers in the minutes going forward.

We believe further improvements are warranted. As we have noted in our prior reports, the RCRC defer or reject only a very small percentage of BSPs – a total of 57 or 8% during this fiscal year – which is a data point worthy of further analysis. Based on our review, it is unclear how RCRC can approve a BSP as written through the end of the current or next ISP year, when: (1) the BSP includes reference to a restrictive control that the RCRC expressly rejects (16 cases over the last two quarters) or for which it requires further justification (43 cases over the last two quarters); or (2) the RCRC simultaneously requires the BSP to be revised and submitted for an updated RAS or RCRC review before the end of the ISP year (92 cases over the last two quarters). In such cases, it would seem 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 contained elements the RCRC found problematic and/or unjustified. We look forward to continuing to monitor and discuss this issue with the RAS in the upcoming year.

### **HRAC Review:**

Quality Trust’s legal team reviews and analyzes the data from the DDS meeting minutes of the Human Rights Advisory Committee (“HRAC”). During this fiscal year, DDS provided us with HRAC meeting minutes from October 2015 through August 2016. We were informed that the RAS would forward us the September 2016 HRAC minutes after the HRAC meeting on October 26, 2016, but we received this data too late for inclusion in this analysis.

From October 2015 through August 2016:

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- HRAC reviewed 1 human rights issue (i.e., closed circuit video monitoring of common areas of residential sites) that affected 10 people being served by a particular provider.
- HRAC reviewed 103 human rights issues for 75 people.
  - 38 (37%) of these issues were about Long Term Acute Care (“LTAC”) placements
  - 31 (30%) were about out-of-state placements;
  - 12 (12%) were about institutional placements;
  - 5 (5%) were about refusals of medication and/or medical appointments or treatment;
  - 4 (4%) were about nursing home placements;
  - 3 (3%) were about requests to change or not to change residences and/or residential providers;
  - 2 (2%) were about concerns in reference to bank accounts, potential exploitation and/or misappropriation of funds;
  - 2 (2%) were about refusals to eat;
  - 1 (1%) was about DDA case closure;
  - 1 (1%) was about a guest protocol;
  - 1 (1%) was about an ineffective BSP;
  - 1 (1%) was about a person receiving a key to his/her residence;
  - 1 (1%) was about a sub-acute care placement; and
  - 1 (1%) was about the use of hand mittens and a liquid absorbent glove.

Over the course of this fiscal year, Quality Trust has made a number of recommendations relating to HRAC, some of which have been implemented, at least in part. For example, in the third quarter, HRAC began clearly documenting in its minutes whether it is approving, disapproving, or deferring a placement, including those that are considered “out-of-state.” Unfortunately, this systems improvement was not sustained in the fourth quarter, and so we ask DDS to direct the HRAC to provide that kind of clarity with respect to its decisions on placements in all of its future minutes. In addition, during the third quarter, we were told that the DDS RAS was in the process of developing a separate DDS form that would require out-of-state providers to supply more relevant information about the life of the person they support, so that it can inform the HRAC review of whether the placement is the most appropriate and least restrictive placement for the person. We have not seen that form referenced in the HRAC minutes for the fourth quarter, and so we ask DDS to direct the RAS to provide Quality Trust with an update on that systems effort.

### **Participation on Committees and Stakeholder groups:**

Quality Trust is an active participant in a number of regular and project related activities with DDS/DDA. The Deputy Director of Programs participates regularly with the DDS Quality Improvement Committee (QIC) and Quality Trust’s Legal Director began serving on the DDA Mortality Review Committee (MRC) in February 2016. In addition, in the past year we have contributed or collaborated with DDS and the larger advocacy community on the following:

- Participated in the DC Olmstead Working Group and submitted formal written comments on the 2016 DC Olmstead Plan
- Participated in the Center for Court Excellence’s Adult Guardianship Project committee, providing input on public resources that are needed to promote less restrictive options for decision-making support within the District

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- Served as members of the DDA HCBS Settings Advisory Group
- Participated with DDS/DDA as a core team member of the Supporting Families Community of Practice. A QT staff member is also certified as a trainer for this project
- Serve as a member of the Center for Court Excellence's D.C. Adult Guardianship and Alternatives Project.
- Advocated for amendments and additional due process protections to be incorporated within DDS' version of DC Bill 21-385 (the Citizens with Intellectual Disabilities Civil Rights Act of 2015), which would reform the District's civil commitment system for people with IDD and codify Supported Decision-Making Agreements. We also attended a series of family and attorney forums to gather stakeholder feedback on the bill, which informed our position.
- Provided comments to DDS on how to incorporate Supported Decision-Making into its Health and Wellness Standards
- Hosted a DC SDM work group made up of families, DC-based private organizations (including the Bazelon Center and the Arc) and public agencies (including representatives from DDS, Department of Aging, and DC Public Schools) to discuss ways to increase knowledge of and access to SDM
- Published an article on SDM for the DC-based American Bar Association
- Submitted testimony to the Committee on Human Services regarding DDS performance in the past year in March 2016 and testified at the budget hearing April 2016.
- Testified at the Committee on Human Services Roundtable on the DDS Director Confirmation Resolution of 2016

### **Presentations and Training Activities:**

Quality Trust also conducted a number of presentations and trainings on topics impacting people with developmental disabilities. Specifically, this fiscal year we:

- Collaborated with ULS/DRDC and DDS to provide training on Supported Decision-Making (SDM) to attorneys on the D.C. Superior Court Mental Habilitation Panel
- Hosted a DC-based SDM symposium that included a presentation by DC Public Schools on its work to implement SDM for students. The symposium was attended by families, professionals, and providers from DC and beyond and provided information on SDM development and implementation in the District and around the country. As a result, DC residents and professionals were given access to SDM best practices and were able to share their experiences with experts from across the nation.
- Presented on SDM at the American Bar Association conference in DC.
- Presented "Supported Decision-Making: What, Why, & How," to both the U.S. President's Committee for People with Intellectual Disabilities and to staff at Legal Counsel for the Elderly.
- Presented at a training series on "Decision-Making & Guardianship: Exploring the Least Restrictive Alternatives" sponsored by the D.C. Working Interdisciplinary Network of Guardianship Stakeholder (WINGS).

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- Presented on “Legal & Ethical Consideration in Representing Clients with Disabilities,” as part of the New Attorney Training sponsored by the D.C. Consortium of Legal Service Providers.
- Presented at the 7<sup>th</sup> Annual Secondary Transition Forum sponsored by the D.C. Department on Disability Services, D.C. Developmental Disability Council, and the D.C. Office of the State Superintendent of Education, among others.
- Presented a training on “What Happens When My Child Turns 18?: Decision-Making Supports for Adults with Disabilities” for parents of students attending The Ivymount School.
- Presented a primer on adult guardianship and alternatives in D.C to the Public Defender Services for the District of Columbia.
- Presented to the Social Security Administration Board on Supported Decision-Making and the representative payee system.
- Presented to the National Council on Disability on Supported Decision-Making as an alternative to guardianship and means of increasing self-determination.
- Presented on District alternatives to adult guardianship, including Supported Decision-Making, to mediators at the D.C Superior Court.
- Presented during the first-ever “federal conversation” about adult guardianship and less restrictive decision-making options, at the request of the U.S. Department of Health and Human Services Administration on Community Living.
- Presented on “What Happens When Students with IEPs Turn 18?: Decision-Making Supports for Adults with Disabilities in D.C.” to D.C. charter schools through the D.C. Special Education Cooperative, to transition-aged students at the Special Education Center at River Terrace, and at the D.C. Office of the State Superintendent of Education annual Local Education Agency conference.
- Presented “Moving Supported Decision-Making into Policy & Practice: A Story from D.C. Schools” for the National Resource Center for Supported Decision-Making’s Spring 2016 Webinar Series on SDM in Education.
- Presented trainings on guardianship, alternatives, and/or QT’s Jenny Hatch Justice Project to the DDS Supporting Families Community of Practice, the DC Coalition of Disability Service Providers, Project ACTION!, Bread for the City, and the UCEDD Advisory Council.
- Presented, in collaboration with DDS and Project ACTION!, on “Legal Advocacy for People with Intellectual Disabilities” for legal interns and new and pro bono attorneys.
- Presented at the annual Reinventing Quality Conference and the National HCBS Conference on “Supported Decision-Making in Action: Emerging Trends and Practices in the U.S.”
- Presented on Supported Decision-Making to staff of the National Children’s Center



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### Conclusion

Review of the individual monitoring data for 177 class members reflects that compliance with the 2010 plan has been broadly maintained. At the same time, we discovered through our other monitoring and advocacy efforts instances where the system breaks down and does not work as designed or planned. While this is not surprising to find in a system comprised of hundreds of providers employing thousands of people and including hospitals, private practice doctors and dentists as well as the community at large, it is also something about which we must pay heed. It is an indicator that the work needed to sustain and improve quality for people with intellectual and developmental disabilities in DC will not end with the conclusion of the *Evans* litigation. Consistent with current expectations for quality systems, DDS/DDA must seek to continually strengthen its ability to identify and remedy individual systems failures before they have significant impacts on people. This will require continued investment in the infrastructure for this agency well into the future.

As we transition to the post *Evans* system of the future in DC, DDS and providers will need to adapt to an ever changing world. There are currently 492 class members in a system of over 2200 people. Non-class members who are younger and have lived at home with family expect a different kind of life. The young people joining the DDS system from DYRS present an entirely different set of complexities-especially in the mental and behavioral health arena. CMS, through their new directives on what community based services and supports must look like will greatly alter the current landscape. Families who have benefited from Early Intervention Services and a generation of post IDEA informed Special Education services bring with them different expectations of what it means to receive services and supports. At the same time, services and systems to address the unique characteristics of the remaining 492 class members must be maintained in order to ensure their health, welfare and opportunity to enjoy true community integration as they face their later years. The leadership team at DDS has indicated an awareness of and willingness to embrace the transitional nature of the current environment. Their ability to take on this challenge is central to better outcomes for people with Intellectual and other developmental disabilities and their families. The effectiveness of internal systems for ensuring and enhancing the quality of services and supports in the District of Columbia is critical if everyone in the system, including the 492 class members is to receive services which offer them the best opportunity to live a healthy and meaningful life.

### Moving Forward

Quality Trust has solicited input from stakeholders on priorities to be addressed through our monitoring activities in the coming year as outlined in our monitoring process. We have reached out to people with disabilities and their supporters, as well as stakeholders such as DDS, ULS, and court officers asking for their input into the issues they would like to see prioritized. Some activities such as review of incidents and investigations, LTAC follow-up and participation on DDS committees like the QIC and RCRC will remain the same. We are also planning to begin individual review for a statistically significant sample of all people currently receiving services in the District of Columbia. This will allow us to review both class and non-class members, who live in a variety of different living arrangements including those who live at home with family. We have also modified our monitoring tool to include questions which will allow us to track several specific outcomes in the areas of: healthcare, community integration, performance of

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Service Coordination and the individual impact of psychotropic medications and Positive Behavior Supports.

We will continue our practice of triaging all Serious Reportable Incidents, randomly choosing investigations involving staff retraining to confirm that DSP's can demonstrate competency, and following people through their placements in LTAC facilities and providing advocacy for anyone who requires it. We have also decided to undertake a thorough review of monitoring tools completed by DDS Service Coordinators to determine if they are uncovering breakdowns in service delivery and ensuring those issues are quickly resolved. We will also be completing our review of 11 deaths at two providers and will share that information with stakeholders via our website.