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First Quarter Fiscal Year 2020 Monitoring Summary

October 1, 2019 – December 30, 2019

Introduction

This is the first quarterly monitoring and lay advocacy report for FY 2020. This report covers the period of October 1, 2019 to December 30, 2019. The report describes Quality Trust's efforts to ensure the adequacy of services and supports for the people being supported through the District of Columbia's developmental disabilities system.

In the first quarter of FY 2020, Quality Trust implemented a new monitoring protocol. The new approach includes elements of our typical monitoring process and incorporates new elements designed to track issues through resolution. Our experience has taught us that some of the traditional elements we measure (e.g., the presence of a current ISP) do not necessarily correlate to the quality of a person's day to day life. So, while having an ISP is an essential requirement within all DD service systems throughout the country, it may or may not result in the delivery of services that support people to live a meaningful life. We meet people who have ISP's that contain all the right words but whose lives are not filled with interesting activities or connected with the larger community. Likewise, we frequently meet people whose plan lacks the kinds of planning we would expect to see in 2020, yet these folks enjoy meaningful relationships and connection with the communities in which they live. This is true because any process or document is only as good as the people who implement it. Three years out from the conclusion of the *Evans* litigation, DD services in DC are still primarily dominated by institutional models of service and compliance with basic requirements. It is not impossible to provide individualized services within the current structure; however, the system does not require or reward providers to implement a truly personalized model. The most typical situation is people with ISP's that contain the right words, but implementation that does not bring those concepts to life for the people receiving services in the District of Columbia. Trying to understand and explain this dynamic is what shaped the methodology we developed for our current monitoring work.

Since the beginning of our work, our advocacy has been available to anyone in DC who requested it. Since 2008, our monitoring has been determined random sample of targeted groups. Thus, while our monitoring data was generalizable, we could not extrapolate what was learned through our advocacy experiences to the full system. Given the transition from the litigation, a significant portion of our prior monitoring focused on ensuring that compliance achieved during the period of court supervision was sustained. The monitoring plan for this year integrates elements of advocacy and monitoring in order to allow us to collect data to answer the following key question: Is there a connection between a person's ISP and the quality of their day to day life?

Methodology

Our monitoring this year is will involve a statistically significant simple random sample of 330 people who are supported by the DC DDA system of services. Our approach will be to meet each person, identify

what has been determined to be important to and for them to live a good life and then assess whether that is being implemented as planned based on what is going on in their lives. As issues or concerns with the activities or services for each person are discovered, we will work with the provider and DDA to resolve these issues. Our staff will stay involved with every person for as long as required in order to ensure that their ISP is supporting the person as originally envisioned. We will complete a monitoring tool designed to measure all the inputs into the ISP, as well as a personal interview and an assessment of the person's physical environment. Once we have reviewed the documentation and gained a perspective on the person's satisfaction with their services, we share the information with the person's team including the Service Coordinator. We will then remain involved in the person's life as the issues of concern are discussed by the team, and ultimately resolved to the satisfaction of the person. It is the integration of monitoring and advocacy that sets this year's monitoring project apart from previous strategies. There are multiple benefits from using this approach. First, we can track to see if services are being delivered as originally planned in the ISP process. We can then assist the person in obtaining the outcomes they prefer, documenting the kinds of barriers that hamper those outcomes. As we gather a large enough body of data, we will be able to identify what drives good services and supports, and if there are any identifiable points where things typically get off track.

Advocacy

During the first quarter of FY 2020 fifty (50) people supported through advocacy. This is a significant increase from any quarter over the past several. The type of advocacy reported in this section is our traditional advocacy requests in which people reach out to us to assist them with solving problems. We will report the numbers related to our new monitoring protocol noted in the monitoring section of this report.

There were eight (8) outcomes met, and three (3) people who decided not to continue. Outcomes included; improved environmental issues, improved family relations, change of day program, acceptance into the DMH, change of residential placement and improved health post hospital discharge. Quality Trust's advocacy process requires consent and participation by the person for whom the advocacy is requested. People may choose not to continue to pursue issues at any time in the process.

Thirty (30) of the referrals this quarter were people new to Quality Trust. The main source of referrals came from within QT, (20/30) or 67%. DDS referrals accounted for 5/30, or (17%). Referrals also came from families, (3/30) or 10%, and self-referrals (2/30), or 7%. Internal referrals increased because Quality Trust navigators and nurses became concerned that an extended amount of advocacy was required to address issues they encountered during the course of their assigned follow up visits on certain Serious Reportable Incidents (SRI's) and Long-Term Acute Care (LTAC) placements,

New advocacy referrals included the following desired outcomes; support to get into DDS, becoming eligible for Medicaid, having SSI benefits reinstated, medical issues that need attention, poor family relations which were causing problems with services and supports, changes in residential placements, changes in day placements and concerns with obtaining medical equipment.

Long Term Acute Care (LTAC) Placements:

During the first quarter, four (4) notifications of Long-Term Acute Care Placements (LTAC's) were received.

People often needed more than one therapy while in LTAC. The most often needed intervention was weaning from a ventilator 50% (2/4) and physical therapy at 50% (2/4). One person also needed antibiotics and dialysis.

There were no concerns that people should be placed in a less restrictive setting.

Serious Reportable Incident (SRI) Follow up:

There were fifteen (15) Serious Reportable Incident (SRI) follow up visits made during the first quarter. Once again, concerns for people experiencing an Unplanned Emergency Inpatient Hospitalization (UEIH) was the most numerous SRI follow up with seven people (7) being assigned (47%). There were four (4) neglect incidents and four (4) abuse incidents also assigned. QT staff were able to meet all fifteen people.

In three cases of abuse staff were removed. In the other case the person was alleged to have been raped by a non-staff member. In all the cases of neglect staff were retrained. All eight of the people who had either abuse or neglect incidents were deemed free from harm.

Advocacy

Active advocacy: 50

Outcomes met/closed: 11

8 outcomes met and 3 closed

# of outcomes met	Outcome
1	Environmental issues resolved
2	Family issues resolved
1	Closed due to inability to receive services (did not meet criteria)
2	Closed because the person changed their mind
1	Changed day program
1	Got into the DMH
1	Waiver service approved for in home support
1	Person's health improved
1	Person moved

Sources of advocacy referrals

QT Internal referrals	Family	DDS	Person receiving services	Outside agency
20	4	3	2	1

Requested outcomes from new referrals

DDA application support/appeals	5
Improved health	7
Follow up after monitoring issues found	4
Residential change	4
Follow up at St. Elizabeth's	2
Access to health services	1
Guardianship issues	1
Abuse at place of employment	1
Housing issues	1
Access to services	1
Educational issues	1
Issues with HSCSN	1
Benefits	1

Number of LTAC follow Up Visits: 6

- We received notification from DDS of six (6) LTAC placements.
- There were no concerns regarding appropriateness of setting at the time of placement
 - One person died

Reason for LTAC (note that people have multiple reasons)	Number of people
Antibiotic Therapy	2
OT/ PT	2
Vent weaning	2
General rehab	1

Serious Reportable Incident Follow Up

Total SRI follow-up: 15 assigned

Incident Type	Number
UEIH	7
Abuse	4
Neglect	4

Post Unplanned Emergency Inpatient Hospitalizations:

- All 7 people were seen

Non-medical follow up:

- All 8 people were seen

Deaths

- There were 9 deaths this quarter
- Ages were 53,60,64,24,80,67,56,77 and 78.
- Average age at the time of death was 62
- Reasons listed on the SRI for death included the following; 3 people found unresponsive, 2 in hospice, 1 murdered, 1 kidney infection and 2 people in hospice.
- The Center for Disease Control and Prevention lists the average life expectancy in the United States is 78.6. The average life expectancy in Washington, DC is slightly lower at 78. This shows the discrepancy between the average age of death last quarter for people with intellectual disabilities (62), and the overall population in Washington, DC (78).

A STORY FROM OUR FOLLOW UP

We worked this quarter with someone at the request of his mother who called to tell us she was concerned the person had experienced medical neglect from his provider. By the time he was transported to the hospital he required placement in the ICU for effects of a delayed drug reaction known as "Dress Syndrome". Thankfully his course at the hospital resulted in recovery. His mother did not want him to return to the same provider, so our staff, working with the Service Coordinator were able to arrange for a transition to a new provider directly from the hospital. He is now settled and successfully living in his new apartment.

Serious Reportable Incidents & Investigations Quarter One FY 2020

Total Incidents	Number closed	Number Substantiated (substantiated & substantiated for neglect and/or abuse)	Total %	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)				Total	Total %				
324	313 (100%)	68	22%	173	33	21	9	304 * 9 investigations were closed without a disposition (3%)	55 %	10 %	7 %	3 %	75%

Breakdown of Serious Reportable Incidents Quarter One FY 2020

N =313 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	133	42%	5%	93% (117 of 133) resolved -no abuse neglect found
Neglect	62	20%	58%	42%
Serious Physical Injury	59	19%	12%	82% (39 of 59) resolved- no abuse neglect found
Abuse	29	9%	38%	62%
Missing Person	13	4%	23%	69%
Serious Medication Error	6	2%	33%	67%
Exploitation	5	2%	20%	60%
Use of Unapproved Restraints	3	<1		
Suicide Attempt	2	<1		
Other	1	<1		
Death	11	N/A	N/A	N/A
Total	324	N/A		

Monitoring Results so far

The data that follows is based on sixty-seven (67) people having been monitored.

- 57 people receive services through the HCBS waiver

- 46 of those 57 people live in Supported Living arrangements
- 21 people are receiving Day Habilitation services, and 6 Day Treatment
- 11 people receive IDS, 8 are competitively employed while 3 receive Supported Employment
- 49% of the sample is between 21-40 years of age
- 33% are between the ages of 41-60 years old
- 45% of the people interviewed spoke to us without assistance from their staff
- 30% have limited spoken language supplemented with gestures
- 87% of the people we met have someone in their life who is not paid
- 35% indicated they are doing what they want to, while 33% indicated they were not
- 45% of the people we have met have environmental issues of concern in their residence, while 53% do not
- The biggest category generating issues/concerns is healthcare at 50%, followed by;
- Issues concerns with ISPs, including goals and objectives and data collection at 37%
- Issues with providers affected 8% of the sample
- Day Program issues were noted for 6%
- Adaptive Equipment and concerns about Service Coordinators were both 6% each
- Behavioral health issues affected 5%, and finally'
- 2% of the people had an issue involving their transportation

QUALITY TRUST LEGAL DEPARTMENT HIGHLIGHT SUMMARY FY 2020, Quarter 1

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, funded through the D.C. Bar Foundation (DCBF) and the WITH Foundation, assists 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. Highlights of our DC legal work for this quarter include:

- Providing legal services in over 100 matters impact DC residents with disabilities.
- Launching the Jenny Hatch Justice Project Health Decision-Making Initiative, intended to promote Supported Decision-Making in the medical field.
- Serving on the DC DDS Home and Community Based Services Advisory Committee, which provides input on draft regulations, policies, and procedures impacting DC residents with intellectual disabilities. This quarter, that work included commenting on draft policies and procedures associated with the new Developmental Disabilities Administration Formal Complaint System, which will officially go into effect on January 1, 2020.
- Serving on several other advocacy coalitions and committees, including the DC-TROV (District Collaborative Training and Response for Older Victims), the Special Education Advocacy Coalition, the DC. Consortium of Legal Service Providers Training Subcommittee, and the DDS Mortality Review Committee.
- Contributing to the University of Minnesota Institute on Community Integration's [Impact Feature Issue on Self-Determination and Supported Decision-Making](#). Quality Trust's work through the National Resource Center for Supported Decision-Making is highlighted in this issue, which includes an article by CEO Tina M. Campanella and Legal Director Morgan K. Whitlatch

summarizing the progress that has been made in advancing the “Right to Make Choices” across the United States, including D.C. This Feature Issue also showcases the success of Ryan King and his family, with a story that brings into sharp relief how people with disabilities can be supported to lead self-determined lives. Ryan was the first D.C. resident to have his guardianship terminated in favor of Supported Decision-Making, thanks to the legal work of Quality Trust’s Jenny Hatch Justice Project.

Conclusion

The first quarter of FY 2020 included some promising signs. DDS announced that two new waivers are on track for submission to CMS in the Spring, with Fall implementation still a reality. The two waivers; one designed especially for people living at home, the other introducing a new degree of self-direction should go a long way to breaking the grip of provider driven, institutional funded services that has been the foundation of supports in the District of Columbia since the 1970’s. In addition, the Creating a Culture of Quality initiative was finalized with a January 2020 kick off date. The Culture of Quality work group is a time limited, task focused, advisory group. Its purpose is to assess the overall structure of quality related activities at DDS and make recommendations to the Director of DDS for modifications and changes to DDS’s quality systems to enhance overall efficiency and effectiveness. The group will achieve this goal by collecting, assembling, and analyzing data relating to the functions of different quality related activities within the DDS Performance and Quality Management Strategy. The group is expected to review a wide range of data, identify where systems align to produce positive outcomes, where gaps exist, and where redundancies are found to eliminate them. These activities will ensure efficient systems that produce desired outcomes for the people being supported through DDS services. The committee shall produce interim reports with recommendations to the Director of DDS. While these developments bode well for the future, there are still significant hurdles to be overcome.