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Fiscal Year 2020 Monitoring Summary

October 1, 2019 – September 30, 2020

Introduction

Fiscal year 2020 began typically as every other year. Efforts to reform the system of services and supports for people with intellectual and other developmental disabilities, in place since the closure of the *Evans* litigation in January 2017, were progressing. Worry about the potential for budget pressures were concerning advocates and families, and the day to day struggle to provide more meaningful support to every person in the DDS system remained inconsistent. Advocates, families, providers and the government were working together to try and find ways to address these concerns and move the system forward.

Quality Trust implemented a new monitoring protocol integrating our advocacy and monitoring into a two-stage process. The modified process was designed to provide the usual snapshot of what is happening for each person reviewed and added an element to provide advocacy for the person after the review was completed that would allow us to track progress with the implementation of recommendations up to the point that any identified issues or concerns were resolved. Our aim was to ensure that issues we found were effectively addressed and to increase buy-in from all team members to promote more effective services in the future.

A significant number of monitoring reviews were completed by the middle of March 2020 when the novel coronavirus completely changed the trajectory of everything, for and about people with intellectual and other developmental disabilities in the District of Columbia. In April and May of 2020, the COVID-19 virus raged; inflicting extensive damage in congregate living models of more than three people. There was also significant spread in Supported Living settings typically consisting of only one or two people. Day programs were forced to shut down and people stayed at home the same as all other citizens in the city. DDS, through the Department of Health Care Finance applied for, and was granted an addendum to the HCBS waiver that put into place several changes aimed at mitigating what was then hoped to be a relatively short duration emergency event. Quality Trust modified it's monitoring protocol to first focus on understanding the how effectively the needs of people with disabilities were being met in different settings, and then, to continue the regular monitoring process through remote methods.

To address the need for greater real time information sharing DDS began to host weekly stakeholder calls. As the pandemic unfolded DC Health played a greater role in the day to day lives of people with disabilities, especially those living in ICF's/IDD and Residential Habilitation. This created both positive and problematic outcomes. DC Health as the centralizing government agency through which all aspects of pandemic response are focused has been helpful. Understanding protocols regarding the use of PPE for instance, and primarily at the outset of the crisis how to obtain what was needed gave providers necessary clarity. At the same time, and there has been an unfortunate bifurcation of expectations for people receiving supports and services. After the Mayor issued her Phase Two Guidelines governing COVID-19 on June 22nd, people receiving services through the HCBS waiver were able to enjoy the same access to their communities as any other citizen of the District. The same has not been true for those roughly four hundred (400) District residents who live in ICF/IDD. This is because DC Health has chosen to treat these District residents in much the same way as people living in

nursing facilities. Anyone with direct experience of the ICF's in the District knows that they are designed as community group homes consisting typically of no more than four (4) residents. This split between how people are treated by DC Health has been one of the most concerning developments of the period between June and the end of September, 2020.

The pandemic is still a serious concern as this report is completed. The struggle to create a system of community services that recognizes the unique character of each person receiving services has been underway for many years. While significant compliance with basic requirements has been achieved, true service quality and effectiveness requires individual application of practice principles in the life of each person based on an understanding of their unique needs. This is achieved through individual negotiation and planning involving all key parties including people with disabilities and their families, providers and government. Unfortunately, people with disabilities still lack any significant power in this negotiation despite the efforts to promote person centered thinking throughout the system. The system that existed in early March of 2020 still too often favored the needs and preferences of providers and DDS over the people receiving services. DDS is commended for leading efforts to engage providers in discussions to help them more effectively balance issues of health and safety with respect for individual preferences and rights. However, there remains very real concern that the COVID-19 pandemic and the inevitable budget cutbacks it will cause over the next few years will set back the progress that has been made in this critical area.

While there is ample reason to be concerned about the future of services at beginning of FY 2021, there is also room for guarded optimism. At the end of 2020 as this report is finalized, two vaccines for COVID-19 are available and more could become available in the coming months. The HCBS waiver recently approved by CMS, called the Individual & Family Support (IFS) Waiver creates a mechanism that will allow District residents with intellectual and developmental disabilities (IDD) who live either in their own home or with family or friends, "to receive HCBS services and supports tailored to their specific needs." The IFS Waiver should enable people to "leverage supports from family or friends so they will not need to rely on traditional residential services." This could help move services closer to a system that is driven by the needs of the people served. The pandemic has also created an opening for a dramatic rise in the use of technology by and with people with disabilities. Although the development was rooted in reaching people virtually who typically were reached in person, experiences during this pandemic have demonstrated that FaceTime, WhatsApp, Zoom and others virtual options can bring people together, engage them in meaningful activities and advance their inclusion into their communities. Finally, we do not know if many of the traditional so called "big box" day programs which have been closed for months will reopen. While there may be some role for buildings in which to provide services for people with developmental disabilities, movement away from reliance on central locations for day service delivery was already underway. This approach to service is not consistent with promoting maximum involvement in community activities. Individualizing day services and right sizing the use of building locations going forward will be a good and necessary development which is long overdue.

This report describes Quality Trust's efforts to ensure the adequacy of services and supports for people supported by the District of Columbia's developmental disabilities system during what has been an unprecedented year. Our monitoring team, which began its work in person switched to virtual remote monitoring on March 16th and remains actively engaged in this process. Our lay and legal advocates have been busier than ever addressing both individual and systemic issues. While so much has been upended in 2020, what has remained consistent is that we are actively involved in people's lives and we are here for anyone who needs our services. We have modified our processes to include additional activities that address the unique circumstances created by the current health emergency and will continue to do so for as long as this challenge is an active concern in our community.

Methodology

The primary goal of Quality Trust's monitoring this year was to collect data from a statistically significant, simple random sample of people who are supported by the DC DDA system of services. Our approach continues to be based on meeting each person, identifying what has been determined to be important to and for them to live a good life and then assessing whether that is being implemented as planned based on what we find going on in their lives. The revised Quality Trust protocol for this year provides advocacy follow-up after the completion of the initial monitoring review. This modified process provides a snapshot of current services and supports for each person reviewed and then advocacy for the person as needed after the review was completed. We 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 then remain involved in the person's life as any issues of concern are discussed by the team, and ultimately resolved to the satisfaction of the person. As additional issues or concerns with the activities or services for each person are discovered, we work with the provider and DDA to resolve these issues. Our staff stay involved with every person for as long as required in order to ensure that their Individual Support Plan (ISP) is assisting the person as needed. It is this 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 the achievement of those outcomes. As we gather a large enough body of data, we will be able to identify what drives good services and supports and will seek to identify any points where things typically get off track as a foundation for informing future system improvements.

We did not complete the collection of enough data during this reporting period to comprise a statistically significant sample given the events of this past fiscal year. That said, the data collected both through our regular data collection process and additional specialized reviews provided valuable data that was shared with DDA and the DDS Director in real time throughout the year. We have included the specific questions and responses in this report to provide insight into the type of questions that are being asked as well as the feedback we are collecting. The data collection will continue in the coming fiscal year and we will report out on the full data set when completed.

Also included in this report are the results of our ongoing review of serious reportable incidents, follow-up on placements in long-term care facilities and the data collected through our independent advocacy activities. Collectively these data are used to inform our larger advocacy agenda for needed systems improvement and legislative change.

Serious Reportable Incidents & Investigations FY 2020

Total Incidents	**Number closed**	**Number Substantiated (substantiated-126 & substantiated for neglect - 74 for abuse-8)**	**Total %19**	**Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)**				**Total**	**Total % 80**				
1231-81 deaths=1149	1120 (97%)	208	19%	639	107	95	56	897 * 15 investigations were closed without a disposition (1%)	57%	9%	9%	5%	80%

Breakdown of Serious Reportable Incidents October 1, 2019 to March 13, 2020

N = 570 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	236	41%	3% (6)	97% (228)
Neglect	111	19%	56% (62)	43% (49) * one (1%) incident closed with no disposition
Serious Physical Injury	98	17%	14% (14)	81% (79) *5 (5%) incidents closed with no disposition
Abuse	64	11%	34% (22) * one incident closed with no disposition	66% (42)
Missing Person	25	4%	16% (4)	84% (21)
Serious Medication Error	16	3%	44% (7)	56% (9)
Exploitation	14	2%	28% (4) * One incident was closed with no disposition	62% 10
Use of Unapproved Restraints	3	<1	33% (1)	66% (2)
Suicide Attempt	2	<1	50% (1)	50% (1)
Other	1	<1	0% (0)	100% (1)
Death	24 * Deaths are not investigated by DDS, so they are not included. ** This number is prior to COVID-19, and represents two thirds of the total in a typical Fiscal Year	N/A	N/A	N/A
Total	**570**	N/A	N/A	N/A

Breakdown of Serious Reportable Incidents March 14, 2020 to September 30, 202

N = 548 closed incidents

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	258	47%	2% (5) One incident closed with no disposition	98% (253)
Neglect	75	14%	53% (40)	47% (35)
Abuse	64	12%	36% (23)	64% (41)
Serious Reportable Incident/ COVID-19	52	9%	2% (1)	98% (51)
Serious Physical Injury	46	8%	22% (10)	78% (36)
Missing Person	26	5%	12% (3) One incident was closed with no disposition	88% (23)
Exploitation	11	2%	18% (2)	82% (9)
Serious Medication Error	8	1%	37% (3) One incident was closed with no disposition	63% (5)
Other	4	<1	33% (1)	66% (2)
Suicide Threat	2	<1	0% (0)	100% (2)
Use of Unapproved Restraints	2	<1	0% (0)	100% (1)
Death	57*	N/A**	N/A**	N/A**
Total	**548**	N/A	N/A	N/A

* This number includes 34 deaths DDS attributes to COVID-19 as of the date this report. The 47 deaths not attributed to COVID-19 represent an increase of 34%

** Deaths are not investigated by DDS, so they are not included.

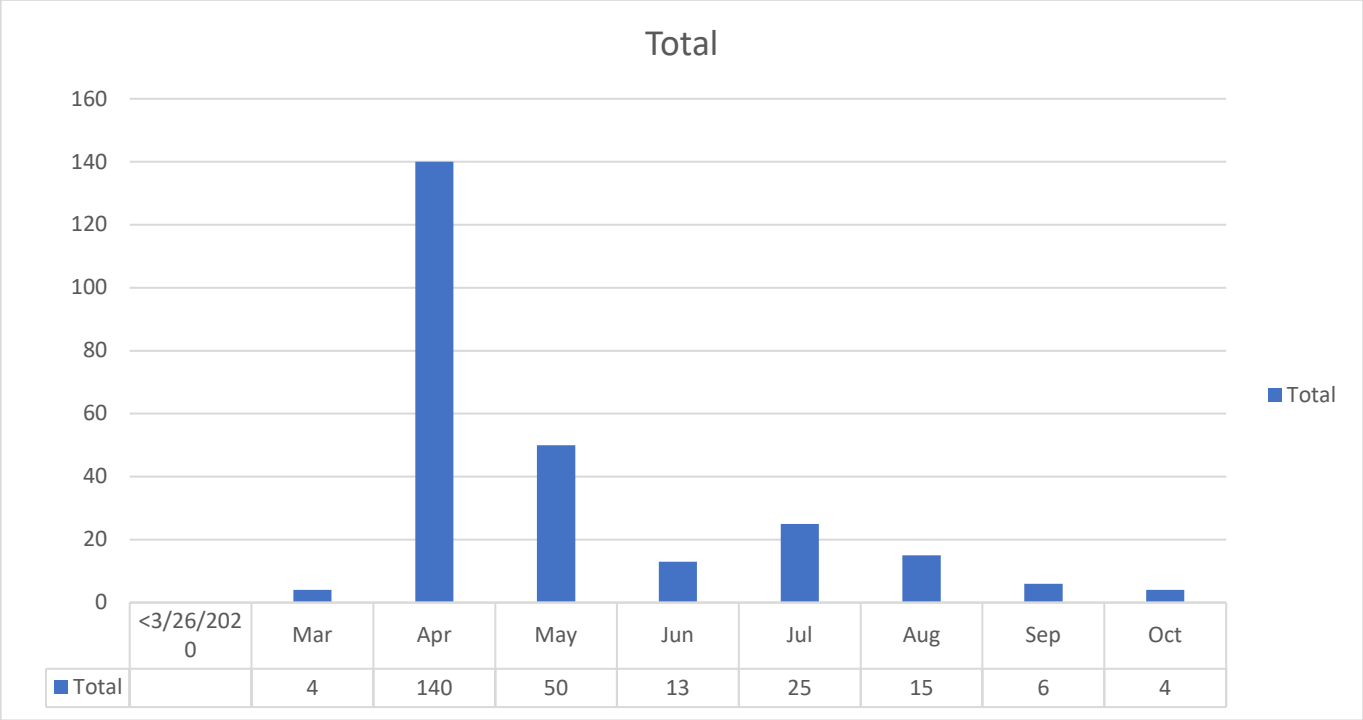
Overall Serious Reportable incident data is remarkably like data from previous years except for deaths, which at 81 rose approximately 125% from previous years. Deaths from COVID-19, at 34, factor heavily into this increase. An increase of 35% separate and apart from COVID-19 however is noted after COVID-19. As the charts above demonstrate, non COVID-19 deaths occurred at the same rate before and after the coronavirus pandemic began (23 & 24). It is crucial to understand the dynamics involved with both the COVID and non COVID deaths. As the Mortality Review Committee completes their review of these 81 deaths, we call on the DDS, working with their contractor, the Columbus Organization to complete thorough investigations of all of deaths. People receiving services must be assured that DDS has developed, at the root cause level an understanding of factors and trends that might compromise the healthcare services they receive. Sharing the results of the analysis with the stakeholder community will go a long way to alleviate concerns about the significant increase in deaths during the Fiscal Year.

1. The 1120 incidents cited in this report are in keeping with totals from previous years.
2. Eighty percent (80%) of incident investigations contained final dispositions of: unsubstantiated, inconclusive, administrative closure, and most numerously resolved-no abuse or neglect found. So, of all the 1120 incidents noted in this report, only 208 contained a finding of causation for the incident.

3. As has been noted in several of our prior monitoring reports, unplanned hospitalizations continue to be the single most numerous category of incident at 494, or 44%.
4. There was a significant decrease in incidents of neglect and serious physical injury in the period March 16 - September 30.
    - Neglect fell from 111 to 75, a decline of 34%
    - Serious physical injury dropped from 98 to 46, a decline of 53%
    - Abuse remained identical, with 64 incidents during each period
    - So too, did missing person incidents with 25 and 26 incidents in each period
    - A new category of incident; Serious Reportable Incident/COVID-19 was created. There were 52 such incidents filed; 39 of those in April and May

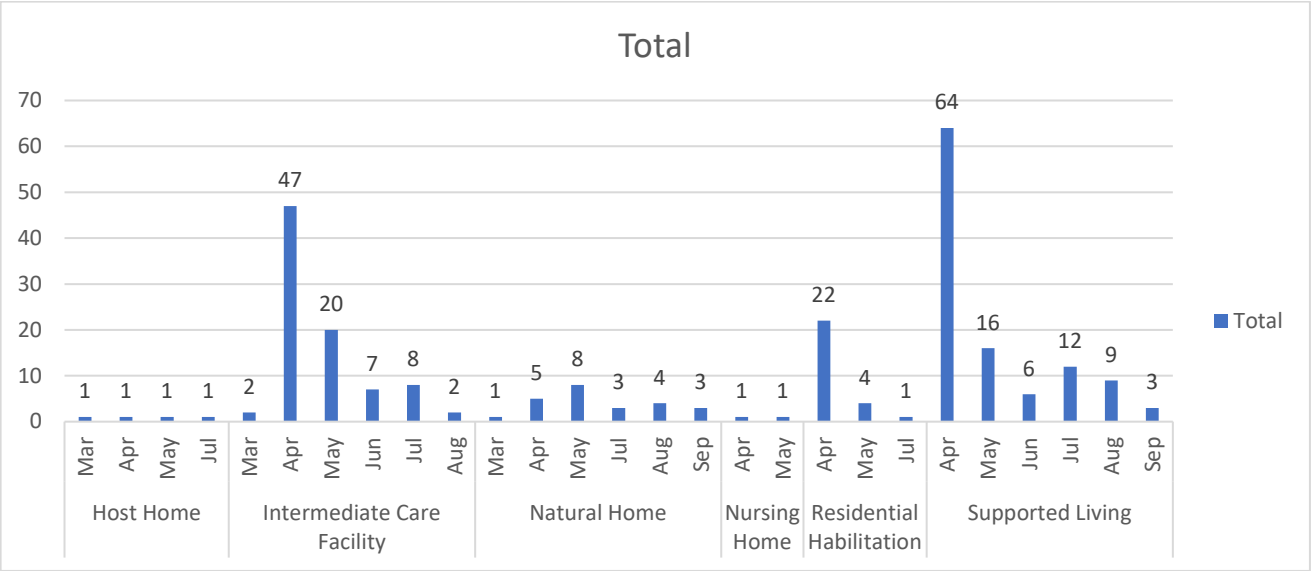
A Closer Look at COVID-19 data

According to DDS data, 256 people contracted COVID-19 since the pandemic began in March. Eighty-two (82) people have required hospitalization, while 140 have not. Thirty-four (34) people have died.



	<3/26/2020	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Total		4	140	50	13	25	15	6	4

The chart below details the month of positive tests by residential service type. As noted above, the pandemic hit the community especially hard in April and May but began to moderate in June.



To put these numbers in context, as of October 1, 2020 there were 2360 people receiving services. Since the inception of the pandemic the safest place to be is at home with family. There are approximately 920 people, or (39%) of all people in the system living at home, but they represent only (9%) of people testing positive. There are approximately 925 people or 39% of all people in the system residing in Support Living arrangements, and they represent 43% of all those who have tested positive. Approximately 280 people live in ICF's/IDD – which is 12% of all people in the system – and they account for 33% of all people who have tested positive. Finally, there are approximately 100 people living in Residential Habilitation homes or 4% of the entire group, and they make up (10%) of all people who have received a positive test.

Aside from an increase in July (25 positive tests), which was twice the number from June (13), but half as much as May (50), the number of people receiving a positive test have been decreasing. The living arrangement with the steepest rise in July was Supported Living with 12 people. While the increase could have been connected to the Mayor's Phase Two Guidelines, which was issued on June 22, it's worth nothing that ICF's/IDD accounted for 8 of the 25 positive tests. Since ICF residents did not experience any increase in community access, it's probable those positive cases were caused by staff. It is also significant, that positive cases in Supported Living decreased in each of August and September. This would seem to undercut the idea that increased exposure to the community would necessarily lead to more positive tests, and further undercuts the continued lockdowns in Intermediate facilities. We have been involved in an effort with other stakeholders to challenge DC Health's position on this issue. We will continue to advocate for a more data driven approach based on collaboration with people with disabilities, their families and other advocates.

Summary of QT Advocacy Activity

- 90 active advocacy cases in FY 2020
- The largest number of referrals came from Quality Trust 30/90 (33%).
- Family members were the second largest category of referrals 23/90 (26%) and then DDS at 14/90 (16%).
- Outside agencies referred 12/90 (13%) people
- Outside agencies that referred people to Quality Trust included: George Washington Hospital, Georgetown Hospital, Psychiatric Institute of Washington, OHCO, Advocates for Justice and Education. HSCSN and Children's Hospital.

Advocacy Referral Source

QT	Family	DDS	HSCSN	Self	Outside agencies
30	23	14	8	3	12

Requested Advocacy Outcomes

- Advocacy referrals often come with multiple outcomes requested. The largest number of referrals made from outside agencies were for support with DDS applications and appeals. DDS referrals often come from the Community Liaison Specialist.
- Quality Trust staff refer people for advocacy based on concerns during SRI follow up, LTAC follow up or monitoring. There were 30/90 (33%) internal referrals.
- Other desired outcomes were support in moving, support in getting out of the hospital, safety concerns, overall health supports, a person desires new DDS SC, behavioral supports, legal issues, follow up after a crime, support after abandonment by family, environmental concerns, waiver application, Medicaid reinstatement.
- 4 people died while receiving advocacy supports and 10 people/families did not follow up.

Outcomes met/closed: 90

Outcomes that were met this year included the following:

- DDS applications being completed
- DDS appeals
- SSI reinstated
- RSA applications completed
- Transportation lined up
- End of life planning
- Support in having Medicaid reinstatement
- Training to staff
- Medical equipment replaced
- Home repairs and environmental improvements
- Released from psychiatric hospital
- Moving to a new home/provider
- Improved relationships
- Job/day support

Follow up for People in Long Term Acute Care (LTAC) Facilities

Quality Trust receives notification anytime a person supported by DDA is moved to a LTAC facility. We conduct follow-up activities to ensure people are receiving the support identified as the reason for the placement and that people return to their home in a timely manner. This following is a summary of activity for this year.

- 33 people were placed in LTAC
- 1 person did not need to go despite notification
- Quality Trust received notice for all placements (100%)
- It was determined by QT nurses that 33/33 (100%) of people were placed in the least restrictive placement.
- 23/33 (70%) of people received additional follow up/advocacy after the initial visit.

- Reasons for follow up were to make sure the person had a smooth transition back to the home or to a new home. The transition includes follow up appointments, getting newly prescribed medications and adaptive equipment and staff training.

LTAC Supports Needed

(most people need more than one support)

Physical Therapy	Occupational Therapy	Ventilator Weaning	Skilled Nursing	IV antibiotics
18	6	6	6	5

- Other needed supports were wound care and trach care

Serious reportable Incident Follow Up

- 33 people received follow up after a serious reportable incident
- The largest number of follow up assignments were for unplanned emergency hospitalizations 15/33 (45%)

UEIH	Abuse	Neglect	SPI	Other
15	7	7	3	1

- 29/33 (32%) people were interviewed by staff
- 7/33 (21%) of people were referred for QT advocacy/follow up
- Staff were removed in all abuse incidents 7/7 (100%)
- 9/15 (60%) pf people hospitalized reported feeling better.
  1 person reported not feeling better.
- 7/33 (21%) of people were referred for QT advocacy

Quality Trust Monitoring Reviews

The methodology for the current monitoring project was described at the beginning of this report. Below are the monitoring questions and responses collected during the completion of individual reviews that are being conducted as part of Quality Trust's overall collection of data for a statistically significant, simple random sample of people who are supported by the DC DDA system of services.

DEMOGRAPHICS 1.2.- Waiver:

Question	Number of Responses	Percentage
Yes	215	86.00 %
No	35	14.00 %
»Answered Question: 250		

DEMOGRAPHICS 1.3.- Type of Residence:

Question	Number of Responses	Percentage
ICF/ID	24	9.34 %
Residential Habilitation	14	5.45 %
Supported Living	133	51.75 %
Host Home	13	5.06 %
Independent Living	3	1.17 %
Family Home	68	26.46 %
Other	2	0.78 %

»Answered Question: 257

DEMOGRAPHICS 1.4.- Day Activity Type (Check all that apply):

Question	Number of Responses	Percentage
IDS	43	14.43 %
Competitive Employment	22	7.38 %
Supported Employment	19	6.38 %
Day Habilitation	85	28.52 %
Day Treatment	17	5.70 %
Employment Readiness	29	9.73 %
Retired	9	3.02 %
Other	39	13.09 %
N/A	35	11.74 %

»Answered Question: 298

DEMOGRAPHICS 1.5.- Age Range:

Question	Number of Responses	Percentage
21-30	65	25.29 %
31-40	60	23.35 %
41-50	31	12.06 %
51-60	52	20.23 %
61-70	33	12.84 %
71-80	12	4.67 %
81-90	4	1.56 %
91+	0	0.00 %

»Answered Question: 257

DEMOGRAPHICS 1.6.- Gender:

Question	Number of Responses	Percentage
Female	90	35.29 %
Male	165	64.71 %

»Answered Question: 255

INTERVIEW & OBSERVATION 2.1.- What method of communication does the person utilize?

Question	Number of Responses	Percentage
Spoken language without assistance	150	42.61 %
Communication device	4	1.14 %
Vocalizations	26	7.39 %
Limited spoken language (needs some staff support)	72	20.45 %
Gestures	53	15.06 %
Facial expressions	45	12.78 %
Sign Language	2	0.57 %

»Answered Question: 352

INTERVIEW & OBSERVATION 2.2.- Does the person require support to answer interview questions?

Question	Number of Responses	Percentage
Yes	108	42.02 %
No	144	56.03 %
Person refused to be interviewed yet agreed to the monitoring process.	5	1.95 %

»Answered Question: 257

INTERVIEW & OBSERVATION 2.3.- Do you have relationships with people not paid to be in your life?

Question	Number of Responses	Percentage
Yes	212	82.81 %
No	14	5.47 %
CND	29	11.33 %
Made a choice not to answer	1	0.39 %

»Answered Question: 256

INTERVIEW & OBSERVATION 2.4.- Is there anything you want to do that you are not currently doing?

Question	Number of Responses	Percentage
Yes	84	32.68 %
No	84	32.68 %
CND	86	33.46 %
N/A	1	0.39 %
Made a choice not to answer	2	0.78 %

»Answered Question: 257

IDENTIFIED CONCERNS 3.1.- Were there concerns noted in any of the following? Check all that apply.:

Question	Number of Responses	Percentage
ISP (including all assessments)	34	6.26 %
Goals and objectives	26	4.79 %
Data collection (ABC, all health interventions, objectives, etc.) poor or missing documentation.	35	6.45 %
Choice & Autonomy	26	4.79 %
Healthcare	73	13.44 %
Day programming/work/school	22	4.05 %
Healthcare (including HCMP, staff training, documentation, clinical services, nursing supports, etc.)	114	20.99 %
Behavioral Health (Plan development, RCRC approval, Psych med reviews, etc.)	24	4.42 %
Unmet goals/desires of the person. Is the person working towards things they desire?	13	2.39 %
Environment	51	9.39 %
Adaptive Equipment (availability, working condition, being utilized correctly, etc.)	28	5.16 %
Service Coordination (Lack of follow up of identified needs, visitation and monitoring tools, etc.)	25	4.60 %
Provider issues (list day & residential. Staff training, staffing, etc.)	64	11.79 %
Transportation	8	1.47 %

Summary of Current Monitoring Project

As noted in the methodology section, our approach to monitoring changed in FY 2020. Combining our typical monitoring protocol with continued advocacy has given us time to follow each person long enough to ensure that our recommendations have been fully vetted and, in most cases adopted. Here are some of the main takeaways from our monitoring activities during FY 2020. The contours of our sample this year were somewhat different than in previous years.

- Fifty-two (52%) of the people we have monitored live in Supported Living arrangements. This is a higher percentage than in the overall system where the percentage is (42%)
- Nine (9%) percent live in ICF's/IDD, which is aligned with the percentage in the overall system; (12%)
- Twenty-six (26%) live at home with their families. Within the overall system there about (38%)
- Sixty percent (60%) of the people we have monitored are between the ages of 21-60, which is in line with the overall system where the number is (89%)
- As has always been the case, almost everyone we have met indicated that they have people in their lives who are not paid. This is a very good sign
- It is not unexpected that the category with the most concerns healthcare at (35%). The kinds of issues we have encountered involve lack of awareness by staff and nurses (usually LPNs) of major health diagnoses and/or current medications and their side effects, but also includes lack of follow through on medical or clinical recommendations. Provider issues, such as staff training (non-medical), knowledge of goals, preferences and needs
- Twenty-nine (29%) of the people we have met were attending a day habilitation program prior to the COVID-19 outbreak, while fourteen percent (14%) engage in Individual Day Services (IDS)
- According to DDS data, 18% of all people in the system (445 people) are working. That is significantly higher than our sample, (13%-competitive employment & supported employment)
- Finally, eighty-six (86%) of the people in our sample receive their services through the HCBS waiver. That is substantially higher than the overall system where the number is 77%

We have been encouraged by the number of people who have welcomed us into their home via Skype, FaceTime or WhatsApp since the coronavirus pandemic forced us to complete our monitoring virtually. For the most part DSP's have been accommodating, and in many cases thrilled to share the activities of their day with us. Overall, we have met younger, and significantly independent minded people during FY 2020. While there have been issues with services as noted above, these issues have not tended to significantly deter people from living the kind of lives they prefer. That said, COVID-19 has significantly hindered everyone from engaging in out of the home activities, day programming and the typical level of community outings and engagement to which they had become accustomed.

Nursing Reviews

Quality Trust also conducted specialized reviews when we identified concerns during the year. Some of these reviews were small projects that targeted only a specific number of people or type of issue. Two specialized tools were developed for reviewing health practices for people. The first focused on people living in Intermediate Care Facilities (ICF) based on the initial spread of COVID-19 within these environments. The second tool was used for people in other settings with a primary focus on those living in supported living environments based on our review of incidents and interactions with providers. We began implementation of this tool in June and will continue execution into the next fiscal year to capture all the people we have targeted. The following are the results of these reviews conducted by Quality Trust nurses.

Non-ICF Setting Nursing Reviews (June to September 30, 2020)

Demographics 1.3.- Type of home:

Question	Number of Responses	Percentage
Supported Living	294	97.03 %
Host Home	5	1.65 %
Natural	3	0.99 %
Residential Habilitation	1	0.33 %

Demographics 1.7.- Is anyone in the hospital with COVID-19?

Question	Number of Responses	Percentage
Yes	0	0.00 %
No	304	100.00 %

»Answered Question: 304

Demographics 1.8.- Is there anyone in the home who has tested positive and is being treated in the home?

Question	Number of Responses	Percentage
Yes	5	1.65 %
No	298	98.35 %

»Answered Question: 303

There has been a significant improvement in the amount (decline) of people that have tested positive for COVID-19 since the beginning of the pandemic in March. In the Supported Living environments that we monitored, (27 agencies out of 47, or 57%) there was a manageable number of positive results during our monitoring work, which began in mid-June. As our data indicate, there was an increase in July, but that declined significantly in August and September. Also encouraging was that there were no hospitalizations. We have been pleased with the knowledge displayed by these provider nurses. Most are going above and beyond to ensure that all COVID-19 precautions are being taken.

People Supported/House Specific 2.1.- Does your home have at least a two-week supply of PPE?

Question	Number of Responses	Percentage
Yes	301	98.37 %
No	5	1.63 %

»Answered Question: 306

People Supported/House Specific 2.2.- Does everyone (staff and residents) wear masks and gloves when they are within 6 feet of each other?

Question	Number of Responses	Percentage
Yes	249	81.64 %
No	56	18.36 %

»Answered Question: 305

People Supported/House Specific 2.3.- Are temperatures and blood oxygen levels of residents taken at least once a day?

Question	Number of Responses	Percentage
Yes	57	18.63 %
No	249	81.37 %

»Answered Question: 306

Temperatures of residents are being checked at least once a day in almost all Supported Living environments. Unfortunately, this is not the case with checking the blood oxygen levels of the residents. We are strongly encouraging all nurses to put this practice into place every morning for each person. Per an article referenced by Respiratory-Research “The Pathophysiology of “Happy” Hypoxemia in Covid-19” (July, 2020) “The remarkable dissociation between profound hypoxemic respiratory failure and a clinically ‘happy’ patient is frequently seen and should prompt physicians and health care workers not only to rely on the patient’s apparent well-being but closely monitor respiratory rate, signs of hyperventilation, oxygen saturation and invasive

measurements of hypoxemia/hypocapnia at regular time intervals. As in the first days of the disease, the lung mechanics are well-preserved and there is no increased airway resistance or dead space ventilation. The respiratory center thus does not sense an uncomfortable sensation of breathing. However, sudden, and rapid respiratory decompensation may occur, and tachypnea and hyperpnea might be the most important clinical warning signs of impending respiratory failure in COVID-19 patients".

Although "Happy Hypoxemia" does not occur in all cases, it does occur. Someone experiencing Happy Hypoxemia will not initially experience any symptoms other than a lower than healthy blood oxygen level; but he/she can decompensate very quickly. Checking blood oxygen levels daily is just another important, non-invasive, inexpensive tool in our healthcare arsenal. It's a tool that can assist us in detecting a potential medical emergency early in the process.

People Supported/House Specific 2.4.- Are staff and residents washing their hands at least once every two hours?

Question	Number of Responses	Percentage
Yes	252	82.62 %
No	53	17.38 %
»Answered Question: 305		

Question	Number of Responses	Percentage
Yes	93	30.49 %
No	212	69.51 %
»Answered Question: 305		

People Supported/House Specific 2.11.- Does anyone in the home work? If they work are, they still working?

Question	Number of Responses	Percentage
Yes, working outside the home	41	13.44 %
No working outside the home	132	43.28 %
N/A	132	43.28 %
»Answered Question: 305		

People Supported/House Specific 2.12.- If the person is working, do they have access to a sink or hand sanitizer at their place of work?

Question	Number of Responses	Percentage
Yes, sink or sanitizer available.	39	12.79 %
No sink or sanitizer	2	0.66 %
N/A	264	86.56 %
»Answered Question: 305		

People Supported/House Specific 2.13.- Is anyone going out into the community?

Question	Number of Responses	Percentage
Yes	247	81.25 %
No	53	17.43 %
N/A	4	1.32 %
»Answered Question: 304		

There are many agencies that are ensuring that the people they support are going out into their communities. A big part of our COVID-19 monitoring for Supported Living homes is reaching out via phone/Facetime to some of the residents. We ask about their desires to go out into the community. Some report that they want to stay home to avoid the virus. Others want to go out and do the things they did prior to the pandemic. Numerous people are going to the places that they want. They are wearing their mask, carrying a personal hand sanitizer, and practicing social distancing. It is important to note that some of the residents are saying that they are not being allowed to go anywhere other than walks in their neighborhood. There are some staff that support this statement. Some of the residents are stating that they would like to go to places like the mall, Walmart, out to eat, or visit a relative, but this is not happening for them. All people should be able to go out into the community if that is their desire and should be educated on how to do so in a safe manner.

People Supported/House Specific 2.14.- If people are going out into the community, are they wearing face masks?: Default

Question	Number of Responses	Percentage
Yes	244	80.00 %
No	8	2.62 %
N/A	53	17.38 %
»Answered Question: 305		

DSP 3.2.- Do you have sufficient relief staff?: Default

Question	Number of Responses	Percentage
Yes	299	97.71 %
No	1	0.33 %
N/A	6	1.96 %
»Answered Question: 306		

DSP 3.4.- Do staff receive updated training on COVID-19 as governmental policies and procedures change?: Default

Question	Number of Responses	Percentage
Yes	305	99.67 %
No	1	0.33 %
»Answered Question: 306		

Provider Policy 4.1.- Are you reporting and tracking all incidents in which staff test positive for COVID-19 to DDS?

Question	Number of Responses	Percentage
Yes	218	71.48 %
No	1	0.33 %
N/A	86	28.20 %
»Answered Question: 305		

Provider Policy Provider Policy 4.5.- Have you reached out to families and guardians of all residents to clarify how you will handle hospital admission and course of treatment, should a resident test positive for COVID-19?: Default

Question	Number of Responses	Percentage
Yes	270	88.52 %
No	9	2.95 %
N/A	26	8.52 %
»Answered Question: 305		

Provider Policy 4.6.- Have you elected to quarantine all residents and identified staff in their homes?: Default

Question	Number of Responses	Percentage
Yes	11	3.59 %
No	292	95.42 %
Yes, but no staff willing.	3	0.98 %
»Answered Question: 306		

ICF Nursing Reviews (March 2020 – June 2020)

Demographics 1.6.- Is anyone in the hospital with COVID-19?

Question	Number of Responses	Percentage
Yes	6	9.68 %
No	56	90.32 %
»Answered Question: 62		

During the most critical part of the pandemic (so far) we completed COVID-19 monitoring for 11 ICF agencies. During this time there were multiple people testing positive for COVID-19, multiple hospitalizations due to COVID-19 (many of them very lengthy) and unfortunately many deaths. Nurses were exhausted and frustrated to see the people in their care becoming so sick and, too often dying. They were also afraid of the unknown. It was that fear that made the early days of the pandemic so troubling.

Demographics 1.7.- Is there anyone in the home who has tested positive and is being treated in the home?

Question	Number of Responses	Percentage
Yes	16	25.81 %
No	46	74.19 %
»Answered Question: 62		

People Supported/House Specific 2.1.- Does your home have at least a two-week supply of PPE?

Question	Number of Responses	Percentage
Yes	50	80.65 %
No	12	19.35 %
»Answered Question: 62		

Some agencies were having difficulties getting the PPE supplies they needed resulting in frustration and fear. We did our best by referring them to online companies that had some supplies still available. Quality Trust worked closely with the DC DD Council who reached out to

resources all over the community. In some cases, they were interested in, and able to provide homemade fabric masks that could be given to agency's in need.

People Supported/House Specific 2.2.- Does everyone (staff and residents) wear masks and gloves when they are within 6 feet of each other?

Question	Number of Responses	Percentage
Yes	54	87.10 %
No	8	12.90 %

»Answered Question: 62

People Supported/House Specific 2.3.- Are temperatures and blood oxygen levels of residents taken at least once a day?

Question	Number of Responses	Percentage
Yes	46	74.19 %
No	16	25.81 %

»Answered Question: 62

Temperatures of all ICF residents were being taken and logged daily. Most ICFs were only checking blood oxygen levels of the residents that were either at high risk for COVID-19 or those that that had been exposed to someone that tested positive for COVID-19. We strongly encouraged all nurses to put this practice into place for every person. Research shows that this is an important measure because it is a reliable, non-invasive, inexpensive way (for some) to determine if they have COVID-19 early in the process. This measure could potentially get a person early medical attention and may help avoid a hospitalization. In that way it could also save a life.

People Supported/House Specific 2.4.- Are staff and residents washing their hands at least once every two hours?

Question	Number of Responses	Percentage
Yes	52	83.87 %
No	10	16.13 %

»Answered Question: 62

DSP 3.2.- Do you have enough relief staff?

Question	Number of Responses	Percentage
Yes	53	85.48 %
No	9	14.52 %
N/A	0	0.00 %

»Answered Question: 62

DSP 3.4.- Do staff receive updated training on COVID-19 as governmental policies and procedures change?

Question	Number of Responses	Percentage
Yes	62	100.00 %
No	0	0.00 %

»Answered Question: 62

Provider Policy 4.1.- Are you reporting and tracking all incidents in which staff test positive for COVID-19 to DDS?

Question	Number of Responses	Percentage
Yes	62	100.00 %
No	0	0.00 %
»Answered Question: 62		

Provider Policy 4.5.- Have you reached out to families and guardians of all residents to clarify how you will handle hospital admission and course of treatment, should a resident test positive for COVID-19?

Question	Number of Responses	Percentage
Yes	60	100.00 %
No	0	0.00 %
N/A	0	0.00 %
»Answered Question: 60		

Provider Policy 4.6.- Have you elected to quarantine all residents and identified staff in their homes?

Question	Number of Responses	Percentage
Yes	29	47.54 %
No	30	49.18 %
Yes, but no staff willing.	2	3.28 %
»Answered Question: 61		

Quality Trust's Nurse Coordinator's Reflection of Challenges Faced in FY 2020

The nursing team at Quality Trust was fully engaged with the many and varied activities normally complete at the onset of this fiscal year. Some of these ongoing activities include providing medical advocacy for people who were placed in Long Term Acute Care Facilities (LTACs), following up on unplanned hospitalizations of concern, providing oversight and assistance to our monitors whenever they situations of significant medical complexity and interacting with and providing technical assistance to provider nurses. All regular activities include significant contact with the person and their support team through in person visits and other follow-up activities.

In mid-March when the COVID-19 health emergency went into effect, everything changed. All nursing facilities shut their doors making in person visits impossible. The same was true for residential homes within the DDS/DDA system, so there too, in person follow-up was abruptly halted. Quality Trust's administration acted quickly to come up with a new plan. All monitoring would be completed virtually. The nursing community in the District's IDD system is small, and people tend to know each other well. It was natural that we would talk to nurses, QDIP's, DSPs and residents via telephone, and ultimately via FaceTime. Once its use became more widespread, we attended every zoom meeting available.

We started COVID-19 monitoring for ICF's in March of 2020. This was to ensure that all agencies were following the proper guidelines as they were quickly emerging from DC Health, the CDC and DDS/DDA. The goal was to keep everyone as safe as possible. There was a great deal of information emerging and we found the initial response was disjointed. Fear played a large part in people's reactions to this unprecedented event. We did a lot of needed education at that time. Sadly, as the data in our report demonstrates a lot of people tested positive for COVID-19 in April and May. Many people testing positive at that time were hospitalized (some for very long periods of time). There were also a significant number of people who died from complications of COVID-19. This included three of the four people being monitored at Bridgepoint Hospital/Rehab as the pandemic began.

It is important to note that the people living in these homes were not leaving their homes. They did not contract the virus from outside. It was brought into them. Some agencies reported having difficulty getting the needed PPE supplies, resulting in frustration and fear among staff members. Quality Trust referred agencies to online resources that might have needed PPE supplies for purchase and reached out to the community for donations. We asked for volunteers to make homemade cloth masks to give to agencies in need or LTAC facilities and were able to purchase small amounts to share with people with disabilities in need. People were also reporting that local hospitals, particularly Washington Hospital Center and Howard University Hospital were so full that, in some cases people waited in hallways waiting for a room to open. People were dying in the hospitals alone. Families were not able to be by the side of their loved ones. Those without families but who had staff who had known them for many years were unable to spend their last moments with a person who deeply cared for and about them.

The RNs from Intermediate Care Facilities expressed significant sadness about these deaths and the circumstances surrounding them. They were afraid and frustrated. Some voiced their sadness and frustrations over the phone. One cried when a person she had known so well had just died. One nurse also shared she had lost her husband to COVID-19.

In mid-June things started to look better. The number of hospitalizations and deaths were decreasing significantly. We finished our work with ICF's and moved forward to do our COVID-19 follow-up with people in supported living and other living arrangements. With over 900 people in supported living alone, this was a huge undertaking for two nurses, but vitally important because this is the largest category of out of the home residential placements in DC and has seen a significant number of positive cases. This monitoring was also important to track the progress for people as the Mayor's order of June 22nd relaxed restrictions for people living in Supported Living arrangements the same for other Washingtonians. There was concern reduced restrictions would create a spike in cases for people receiving these services. Again, as our data reveals that was not the case. We were pleased that most agencies were now reporting that they did not have anyone hospitalized due to COVID-19 and there were no new deaths. Staff's positivity rates had also been reduced.

Things were stable in the DD community at the end of the fiscal year. We found that most residential nurses were doing a good job with everything COVID-19 related. PPE equipment now seems to be plentiful and staff and residents generally report that they are following the proper protocols. We are hopeful that the vaccine for COVID-19 will be available for all staff and residents supported by DDA by the summer of 2021. A big part of our COVID-19 monitoring for these homes is reaching out via phone and FaceTime to some of the residents. We ask about their desires to go out into the community. Some report that they want to stay home to avoid the virus. Others want to go out and do the things they did prior to the pandemic. Numerous people are going to the places that they want to go. They are wearing their masks, carrying a personal hand sanitizer, and practicing social distancing. A smaller number of people still report that they are not being allowed to go anywhere other than walks in their neighborhood, so helping people to balance health and safety with remaining active and involved with others and the community remain an issue to be addressed.

As this report is being finalized, we are seeing new cases of COVID-19 increase significantly. Although safety is very important, it is vital that agencies understand that and as long as people have been educated on the risks of COVID-19 and are following the proper guidelines, there is no reason that people should not be allowed to go out into the community and receive visits; especially from the families and close friends. Indications are that we could be several months away from brighter days so it is important to remember that safety does not just mean avoidance from COVID-19, it also means being equally as vigilant to the fact that our mental health is as important as our physical health during the pandemic.

Conclusion

Fiscal Year 2020 was a year unlike any other year. The COVID-19 pandemic literally changed everything. The virus changed life as it had been known for everyone – including people with disabilities. Day programs closed, the Mayor's initial stay at home order created a "lockdown" situation in which most people did not leave their homes from March until the middle of June unless they were considered an essential worker. The category of essential worker did include some of the people supported by DDA who worked in businesses that remained open. As noted in this report, the period of April and May saw the greatest numbers of positive cases, hospitalizations, and sadly many deaths. Thankfully however, the crisis began to abate in mid-June, and remained manageable throughout the summer. The virus appeared to be coming under some level of control at the end of the fiscal year as the data in this report indicates. The promise of a vaccine winding its way through

the community means there is hope in sight for a more typical life sometime in the future – perhaps even before the end of 2021.

The main issues of concern that emerged this year are not new or surprising. For too long decision-making and the power to decide what will or will not happen to and for people with developmental disabilities in DC has resided with providers and the government even though this system exists to support people with intellectual and developmental disabilities live meaningful lives and exercise their rights as citizens. While DDS/DDA continues to promote person centered practices, the ability to effectively balance health and safety issues with support for individual choice and preferences within the provider community is limited. DDS/DDA began the process of dialogue with providers about how to effectively address this concern, however fears within the community about poor health outcomes and liability continue to impact they type and quality of supports people with disabilities receive in their quest to live life consistent with their individual choice and preferences. Quality Trust will continue to advocate for the support needed to increase this capacity within the system. Future progress in systems improvement will not occur without achieving this goal.

Unfortunately, as previously noted, the District, Maryland and Virginia has seen a period of increased daily cases in the first quarter of FY 2021. A substantial spike will extend the period that all members of the community will need to remain vigilant in order to protect ourselves and others from the virus. And even with the promise of receiving a vaccine, continuing to wear PPE and practice good hygiene will be crucial for the foreseeable future. Quality Trust will continue to actively monitor the impact of these circumstances for people with disabilities. Continued limitations on visits from family and friends, and lack of meaningful engagement in activities or with others could create substantial risk not only to people's progress on goals and outcomes, but also to their mental health. Providers will need to find ways to keep people physically and mentally active and create multiple, varied opportunities for meaningful engagement at home. We will also need to be collectively planning for when the virus does fade and there is the opportunity for re-engagement in the community. The fiscal impact of this pandemic is likely to limit any new funding and require the building of new services and supports for people with existing or more limited resources. While this is not a preferred outcome, it may provide an opportunity for new thinking. Greater autonomy and less reliance on formalized services and supports could go a long way to assisting people with disabilities to lead more fulfilling lives as more integrated and engaged citizens within our community.