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Fiscal Year 2023 Monitoring Summary

October 1, 2022 – September 30, 2023

Executive Summary

This report describes work completed by Quality Trust's monitoring and advocacy staff during Fiscal Year (FY) 2023.

With implementation of the Developmental Disability Eligibility Reform Amendment Act of 2021 (DDERAA) beginning on October 1, 2022, we anticipated more requests for assistance with applications to the Department on Disability Services (DDS) due to changing eligibility requirements for services from the DC Developmental Disabilities Administration (DDA), but that was not the case. Another year will be necessary to see an increase.

Our random monitoring began to provide us with data on the District's implementation of the Centers For Medicare and Medicaid Services (CMS) new Settings Rule within the Home and Community Based Services (HCBS) Medicaid Waiver.

Our triage of Serious Reportable Incidents (SRIs) and follow-up on select incidents once again found significant problems with documentation, communication, and training within the provider community.

As part of DDS's participation in the National Core Indicators (NCI) project, we completed 300 in-person interviews of people receiving support and services enabling data from the District of Columbia to be included in the national dataset for the first time in several years.

This report will detail analysis of data from our monitoring and advocacy on behalf of people with disabilities during the year as well as important issues that will impact DDS, providers, and people receiving services in FY 2024 and beyond.

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Introduction

This report covers the work completed by Quality Trust's monitoring and advocacy staff during FY 2023.

The report touches on two broad issues that helped define FY 2023, including the continuing decline in the spread of COVID-19 infections and implementation of the District's Medicaid Waiver programs for people with intellectual and developmental disabilities (IDD). We have also included individual stories that we hope illustrate the positive outcomes but also breakdowns that continue to appear within our serious reportable incident (SRI) triage and follow-ups.

COVID-19: Year Four

The COVID-19 pandemic hit with significant impacts for everyone in mid-March 2020. Detailed attention to the effects of the pandemic on people with disabilities receiving services, the staff who support them, and the initiatives put in place by DDS to combat and mitigate those effects was included in our last three Annual Reports.

2023 showed a great decrease in COVID-19 cases and demonstrated that the initiatives put in place by DDS, as well as increased vaccinations across the country, have helped decrease the effects of COVID. Only 11 people supported by DDA were hospitalized for COVID-19 in FY 2023 with no subsequent deaths. Since the first documented case, 833 people supported by DDA have been diagnosed with COVID-19.

We noted last year that the landscape of day activities would be permanently altered by COVID-19, transforming day supports away from larger day habilitation models to home-based companion services. This change has been an opportunity to provide people with meaningful opportunities for engagement when they could not leave their homes and then continued to provide community outings and integration activities when the COVID numbers decreased. For people enjoying enhanced Companion Services that were available only because of the flexibility granted during the COVID-19 Public Health Emergency (PHE), those services are set to end in November 2023. Many people will be expected to transition back to either day programs or employment services. There are exceptions for retirees, people who had five (5) days of companion approved prior to the PHE, and people with a documented health or medical reason that prevents them from engaging in other day programs or employment services.

Quality Trust has met families through advocacy and monitoring who want their adult children who are living at home not to return to large day programs. Reasons cited were issues with safety, reliable transportation to and from day habilitation, and the lack of quality programing. One mother stated her son would previously go sit in a mall doing nothing all day, with little staff interaction while in day habilitation. Advocates in DC will need to remain vigilant to ensure more person-centered options for working and day program activities enjoyed by many during COVID are maintained.

National Core Indicators

National Core Indicators (NCI) is a "national effort to measure and improve the performance of public developmental disability agencies." For the first time this year, the District of Columbia subcontracted with Quality Trust to complete 300 in-person interviews of people supported by DDA to gain insights into the satisfaction with their services. The data was collected by the national NCI partners and a summary and report of DC's performance will be available on their website – https://idd.nationalcoreindicators.org/ - during FY 2024.

FY 2023 HCBS Medicaid Waiver Implementation

The Intellectual and Developmental Disabilities (IDD) and Individual and Family Support (IFS) Medicaid Waivers are DC's primary funding sources for community-based, long-term support for people with IDD. Concluding a long period of planning and execution undertaken during the pandemic, DDS/DDA received approval for a renewal of the IDD Waiver and an amendment to the IFS Waiver in the fall of 2022, which are comprehensively described in Quality Trust's FY 2022 Monitoring Report.

Although we advocated for one person who specifically requested services under the IFS waiver in the last year, we did not experience the significant increase in requests for advocacy around eligibility for services and/or transitioning between the waivers that we anticipated. While supporting the person in applying for the IFS waiver, it was noted that there was significant confusion within DDS intake staff about the new eligibility requirements and processes required by the DDERAA and in the Waiver applications approved by CMS. It is our understanding that Disability Rights DC (DRDC) received far more requests for assistance, so they have more insight into successes and challenges with applications under the new Waiver rules.

In addition, we anticipated an increase in requests for participant-directed services (PDS) through the IFS Waiver. Again, we did not see any change in our advocacy requests asking for PDS.

We were hopeful that the changes made to DC's waiver services would lead providers to adapt their business model in response to self-direction, increased use of remote supports and monitoring, increased use of assistive technology, and to allow for greater control and autonomy by people with developmental disabilities. As FY 2023 ended, that has not been the case. We anticipate a significant increase in requests for assistance with these matters in FY 2024.

FY 2023 Monitoring and Advocacy Results

Monitoring Methodology

Our random sample monitoring in FY 2023 involved a follow-up on the implementation of the District's transition plan created to implement the mandates within the "HCBS Settings Rule," a directive from the US Centers for Medicare and Medicaid Services (CMS). The "HCBS Settings Rule" was finalized in 2015, and CMS originally gave all states until 2020 to develop an approved transition plan that would move their IDD system away from top-down, provider-driven services and give people being supported more choice and autonomy. The pandemic pushed the expected implementation date from 2020 until 2023. The District of Columbia's plan was the first to be approved by CMS.

Our monitoring tool for FY 2023 was completed for a group of people chosen through a statistically significant random sample with questions developed to assess the District's ability to provide meaningful opportunities for choice and autonomy.

Preliminary Random Monitoring Results

Our random sample was drawn from a list of all people receiving services from DDA. The focus of our monitoring was the extent to which DDS has created opportunities for meaningful control and autonomy over one's services within congregate residential living per the implementation plan for the new HCBS Settings Rule. Our results this year are only preliminary because we were not able to complete a statistically significant sample. We are continuing our monitoring in 2024 and hope to share results of the full monitoring project in next year's report. Preliminarily, we can share that while initial steps were taken, there was a decided lack of understanding at the level of direct support staff of the new expectations and their role in ensuring the people they support exercise more meaningful autonomy.

See Appendix A for preliminary data.

FY 2023 Serious Reportable Incident (SRI) Breakdown

Incident Type	Number FY 2023	Percentage of Total Incidents FY 2023	Number FY 2022	Percentage of Total Incidents FY 2022	Change from FY 2022 to FY 2023
Abuse	139	12%	116	10%	+20%
Death	41	4%	39	3%	+5%
Exploitation	43	4%	55	5%	-21%
Missing person	66	6%	89	7%	-26%
Neglect	282	24%	358	30%	-21%
Serious Medication Error	19	2%	27	2%	-30%
Serious Physical Injury	130	11%	113	10%	+15%
Suicide Attempt	6	<1%	9	1%	-33%
Unplanned Emergency or Inpatient Hospitalization (UEIH)	404	35%	366	31%	+10%
UEIH/COVID-19	11	<1%	9	1%	+22%
Other	9	<1%	3	<1%	+200%
Repeated use of Emergency Restraints	0	0	2	<1%	-100%

Use of Unapproved Restraints	0	0	2	<1%	-100%
Total	1150	100%	1188	100%	-3%

Our data on Serious Reportable Incidents reveals that, overall, the number of incidents - including deaths - remained remarkably consistent with years past, with movement up or down within specific incident categories. The most notable change was the substantial increase in unplanned hospital admissions. With the introduction of the new telehealth initiative, we had anticipated a reduction.

- Overall, the number of incidents was consistent with last year (three percent decrease).
- There was a decrease in allegations of exploitation, missing person, serious medication errors, and suicide attempts.
- There was a significant decrease in neglect allegations. It is unclear why there was a decrease, but it is possible that the lack of formal day programming for many people and lack of community involvement due to COVID may have offered less observation from outside communities who often report observing neglect.
- There was a significant increase in unplanned emergency inpatient hospitalizations (UEIH). This finding undercuts the hope for impact of the new telehealth initiative and requires in-depth study. Data from DDS on this finding will help advocates better evaluate the success of the program.
- DDS staff reported 157 incidents. The largest reporting group was Service Coordination (13%).
- Five (5) incidents of neglect were reported by Quality Trust staff (2%).
- In abuse incidents, residential staff are the target of abuse claims 76% of the time, followed by family members being alleged targets 11% of the time.
- Verbal and physical abuse both accounted for 40% and sexual abuse accounted for 9% of abuse incidents.
- Police were called just 7% of the time for abuse allegations despite half of allegations being for physical or sexual abuse.
- 42% of people who alleged sexual assault went to the hospital for initiation of a rape kit.
- 38% of neglect incidents were due to staffing issues.
- 22% of neglect incidents were related to a person's healthcare.
- 28% of Serious Physical Injuries were caused by a fall, followed by incidents of unknown origin at 24%.
- 80% of people leave home on purpose in a Missing Person Incident. Only 5% of people were "lost."

<u>Unplanned Emergency Inpatient Hospitalization (UEIH) Triage</u>

N=404

Quality Trust's Healthcare Coordinator, a registered nurse (RN), is now assigned to triage all UEIH's. See Appendix B for QT Nursing Monitoring data.

- 75% percent involved medical issues
- 25% involved psychiatric/behavioral issues

- 43% required continued advocacy from our team
- 55% either had their discharge recommendations followed or had the recommended appointments scheduled
- 38% had a Health Care Management Plan, a Physician's Order, and a Health Passport that matched
- 88% percent of people were involved with the Health & Wellness unit within the Developmental Disabilities Administration

Consistent and accurate healthcare documentation remains a problem. People receiving nursing services are expected to have a current Physician's order (POS), Health Care Management Plan (HCMP), and Health Passport (HP) that have matching diagnoses, medications, and recommended interventions. The fact that only 38% of these required documents were accurate is a concern. These documents are the foundational building blocks to appropriate healthcare within the Developmental Disabilities Administration system. Without the correct guidance from these essential documents, healthcare is compromised and it is nearly impossible to continue to build a strong healthcare plan for the people who need and deserve it.

Another concern that we identified involves several serious injuries, the origin of which is unknown. As an example: An 86-year-old man, who lived in an ICF, had some swelling of his left shoulder. He was sent to the emergency room, and it was determined that he had sustained a left shoulder fracture. The origin or cause of the injury was unknown. This was a man who required a walker and constant staff support to navigate his surroundings. We were concerned with the lack of provider transparency in reporting this incident. It is important to note that a forensics investigator from DDA was also involved in this case. Sadly, the gentleman passed away while in the hospital.

On a positive note, DDS' Health & Wellness unit was involved in 88% of the unplanned hospitalizations. While reviewing their notes in MCIS, Quality Trust nurses found that they visited the person in the hospital, spoke with the attending physicians and nurses on a regular basis, and attended most discharge meetings. They also followed up with each person in their home or via phone call once they were discharged from the hospital.

<u>UEIH In-Home Follow-Up</u>

N = 61

After triage, an RN is then assigned to conduct follow-up monitoring for all UEIH's that are deemed medically complex (i.e., multiple admissions, multiple comorbidities, age, etc.). The RN visits the person in his/her home and completes a follow-up based on the specific incident. We ensure that all recommendations have been completed or are in the process of being completed and that all medical equipment has been obtained (and current equipment is in good working order). We also ensure that staff have been trained on the Health Care Management Plan and are knowledgeable about any new medical concerns. If staff are not deemed knowledgeable, Quality Trust nurses connect with the agency registered nurse/QIDP and recommend immediate training. Each person was deemed safe from harm upon the close of each follow-up.

Multiple Admissions for The Same Issues

N = 80

Medical hospitalizations made up 75% of all hospitalizations. 54% had multiple admissions in the last 12 months, and 26% had been admitted multiple times for the same issue.

While reviewing people who had multiple admissions for the same reasons, numerous concerns were noted by our nurses. We observed a clear lack of sound clinical judgement on the part of the registered nurse and/or the primary care provider on numerous occasions. There was also a lack of staff training and/or sloppy documentation. Only 38% of the people had adequate nursing documentation or accurate physician's orders in place (i.e., updated Health Care Management Plan, Health Passport, and Physician's orders).

Example: a 71-year-old woman, with a history of refusing her annual mammograms, was sent to the emergency room multiple times, and was admitted on a few occasions. This was due to symptoms such as back pain, shoulder pain, and burning in her breasts. Again and again, staff from the hospital recommended orthopedic follow up, and, in turn, the Orthopedic doctor recommended physical therapy (PT). This person did follow up with orthopedics and PT on numerous occasions, but these follow-ups did not result in a reduction of her pain. A year later, it was discovered that she had stage IV metastatic breast cancer, which had spread to her bones. The registered nurse/primary care provider should have been able to look beyond the hospital/orthopedic recommendations and put together the "clinical puzzle" themselves, sending her for the appropriate diagnostic testing. This is not to say that they could have caught the cancer before it reached stage IV, but they could have avoided multiple emergency room visits and hospital admissions and secured her treatment earlier.

Psychiatric Hospitalizations

N = 100

Psychiatric hospitalizations made up 25% of all hospitalizations. 88% had multiple incidents. There were several people who accounted for most of these numbers. 67% of the people were involved with CPEP (Comprehensive Psychiatric Emergency Program). Although 79% had police involvement, quite a few of them were due to police escorts to the hospital for safety.

Long-Term Acute Care (LTAC) Follow-Up

N=26

Quality Trust nurses follow up on every DDS LTAC placement notification to ensure that the person does not stay longer than is medically necessary. They review each placement, track each person throughout the placement process to ensure that the identified outcome is being achieved in a timely manner, and they conduct follow-up visits after discharge. These follow-up visits are necessary as they ensure that all discharge recommendations have either been met or are in the process of being met. They ensure that all staff have the proper updated training, all documents are updated, all recommended medical equipment has been obtained/or previous

equipment is in good working order, and that the person is going back to the safest environment possible.

Of the 26 LTAC follow-ups that Quality Trust nurses completed in FY 2023:

- 20 (77%) were recommended for limited stay
- 26 (100%) were found to be in the least restrictive environment by QT nurses
- 26 (100%) were reported by DDS
- 14 (53%) required nursing advocacy follow up after being discharged from a LTAC placement
- 8 (31%) could not return to their previous home after they were discharged due to the number of supports required and the placement becoming unsustainable for the person

Reason for LTAC placement:

*Note that people can be admitted for more than one support.

- 16 (62%) received OT and/or PT
- 3 (12%) received IV antibiotics
- 4 (15%) received wound care
- 1 (4%) received tracheostomy care
- 1 (4%) received TPN (Total Parenteral Nutrition)
- 2 (8%) received other skilled nursing services

Nursing shortages continue to be observed at LTAC facilities, which can result in long waits for required care such as using the bathroom, assistance with eating, having adult protective undergarments changed, and being repositioned. This can lead to a longer duration of stay and additional procedures (e.g., wound care, treating injuries from falls while at the LTAC, treating LTAC-acquired infections).

Several people have been discharged home from rehabilitation without DDS or Quality Trust's knowledge (QT nurses were involved with three of these cases). This is a major concern because without the needed follow-up, the person may be returning to an unsafe home environment. Improved communication between the LTAC's, DDS, and QT would be beneficial and help to avoid this problem.

Deaths

Over FY 2023, the number of deaths, 41 people, was in line with 10-year historical averages. While this was an increase from FY 2022, the increase was only 1% and was a significant decline from the COVID years of 2020-2021.

Quality Trust reviewed 22 (54%) of the subsequent Columbus Death Investigations for basic data and trends.

- 59% of people died in the morning hours while generally the overnight shift was working.
- 55% of people died between October and January

- 77% of people lived in a residential setting outside their natural home with supports from a provider
- 55% of people died in their home
- 27% of people died in the hospital
- 6% of people were receiving hospice
- 95% of the deaths were determined to be natural by the DC Medical Examiner
- One death was determined to be unnatural and was due to a drug overdose
- 36% involved former residents of Forest Haven
- The average age was 57: the youngest person was 27, while the oldest was 83
- Recommendations for the person's residential provider included the following: 59% needed to improve the person's HCMP, 68% needed to improve the Health Passport, and 59% had a physician's order that was inaccurate or didn't match other health documents. These problems with documentation are in line with the results of our monitoring over the past several years.

Life expectancy in Washington, DC is 75.3 years according to the National Center for Health Statistics.[1] The average age of death for people we reviewed was 57, over 18 years shorter.

While the age of death for DC residents with IDD was lower than the average DC resident, it is reported that the average age of death for people in state intellectual and developmental disabilities systems was 50.4-58.7 and 61.2-63 years in Medicaid data.[2]

While the average age of death is similar to data from other state IDD systems, it is several years lower than the range reported by Medicaid data. However, direct comparisons must be used with caution as data is typically provided by states, and while DC is considered a state in this case, it most closely resembles a large city within a state. A better comparison could be made to other metropolitan areas within states, but we have not been able to access data of that sort.

While it is widely known that people with IDD have higher mortality rates and are younger at the time of their death, little seems to change in related healthcare interventions and preventative care. Our monitoring data reflects what Columbus Investigators also found; healthcare documents are often poorly written, contain inaccuracies, and lack pertinent data. Only 27% of people we monitored living in an ICF had a Physician's Order, a Health Passport, and a Health Care Management Plan that matched. This coincides with UEIH triage data that shows only 38% of people reviewed had matching healthcare documents.

There continues to be concern over staff response regarding the length of time symptoms were present prior to unplanned admission and the initial calls to nursing staff and the PCP.

[1] National Center for Health Statistics, National Vital Statistics System, 2021 death data. https://www.cdc.gov/nchs/pressroom/states/dc/DC1.htm

[2] "Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data" Emily Lauer and Phillip McCallion. September 2015 https://pubmed.ncbi.nlm.nih.gov/25994364/

People We Met in 2023

Our reports contain a lot of data. It's easy to lose the human element in long reports filled with data. That is why we decided to include stories of several people we have met and supported through the SRI triage and LTAC follow-up processes used at Quality Trust.

We have highlighted several people we supported in 2023 below. Some are former residents of Forest Haven, and some are not. Some are young and others older. Many have medical comorbidities and psychiatric conditions. This group is typical of the people we meet as are their needs. The names used in these stories are not the person's true name and were used to protect anonymity.

James

We met James, a 69-year-old man, through our triage process when he was admitted to the hospital in the fall of 2022 for low oxygen levels. He was discharged from the hospital to a LTAC placement and was again followed by our internal process of supporting everyone through their LTAC placement. Nursing advocacy was provided for three months after his LTAC discharge without further incident.

Another incident occurred, and he was admitted to the hospital again. He was intubated while in the ICU and later discharged to a rehabilitation setting. We followed him through his second LTAC stay until he was discharged home.

Once home, another SRI was communicated involving a rib fracture and bleeding. The injury was of unknown origin and James died in the hospital without returning home.

Paul

Paul, a 44-year-old man, is another person we met through the SRI triage process. He had more Serious Reportable Incidents than any other person in the DDS system during FY 2023. He chooses to leave his residence and does not return, citing his preference to visit friends. The use of drugs is also noted in many of these instances. These incidents are categorized as Missing Person incidents, though he is simply unaccounted for by staff from his residential provider. He does return at times of his choosing rather than the choice of his group home staff.

Paul began receiving DDA services in 2020, prior to which he was homeless. He has mental health diagnoses and a history of alcohol, cocaine, and opioid dependence. In the spring of 2023, Paul completed a 28-day inpatient program for substance abuse but relapsed shortly after. Through the triage process, Paul was offered support by a Navigator to reconnect with an agency that could support him through a long-term recovery program. Paul accepted this offer and is at the drug rehabilitation center as this report is being written. Quality Trust will continue to support him through advocacy after discharge from the program and offer support in maintaining his recovery.

Janice

Quality Trust met Janice when her Godmother called with questions and concerns about her Goddaughter's team as well as her behavioral supports. Janice was a young woman who experienced trauma, depression, and other psychiatric diagnosis. She often refused to leave her apartment and has been involved with routine bouts of aggression towards her direct support staff.

When we met her, she had a legal guardian, an involved family, and a full team of professionals to support her, but it was reported during the initial call that infighting amongst the team was causing significant concern. Communication was poor and members did not respect each other and could not agree on how best to move forward. The friction was affecting Janice and her care. It had been recommended that Janice be admitted to a psychiatric hospital for stabilization and the team had varied opinions about whether this should happen.

Quality Trust met Janice and all the members of her team, actively listening to the various opinions and stories told by the different team members. It is not uncommon for our staff to become involved in these types of contentious team dynamics. As we always do, we reviewed records to ensure appropriate behavioral and psychiatric supports were in place, and staff were interviewed to understand their training levels and perspectives. Many times, staff who know the person best provide invaluable information and unique perspectives on practical solutions.

After the initial gathering of information, it became evident that there was one team member who was providing false information to other team members and causing much of the confusion and infighting. This team member was replaced, and communication and coordination improved. Behavioral and psychiatric supports were put in place and staff were trained. While Janice continued to struggle with psychiatric issues and resulting behavioral incidents, her team no longer engages in the kinds of counterproductive infighting that marked previous meetings. Her team is clearer and more unified about what supports they think will be helpful. As a result, recommendations are more easily and quickly implemented. Rather than arguing with each other, they could focus their energy on Janice.

Jon

Jon is a 44-year-old man who was discharged from St. Elizabeth Hospital in 2009 and is supported by DDS and the Department of Behavioral Health (DBH). He has a 2:1 staffing ratio 24-hours a day to support his behaviors of physical aggression.

In the last year, Jon has had 58 Reportable Incidents, twenty-five of them being visits to the emergency room and 12 SRIs for unplanned psychiatric hospitalizations. See the chart below.

Incidents from 10/1/2022 to 9/30/2023	
Total incidents	58
Emergency room visits	25
Psychiatric hospitalizations	12
Abuse	1
Missing person	3
Relocation	1
Property destruction	2
Incidents involving police that are not SRIs	12
Other	2

Jon’s hospitalizations are due to extreme agitation which leads to physical aggression towards residential staff and medical staff in the emergency room and at doctor’s offices. These incidents are followed by police involvement leading to his being transported to the Psychiatric Institute of Washington (PIW), Comprehensive Psychiatric Emergency Program (CPEP), or to the Washing Hospital Center psychiatric unit. When Jon recently started receiving residential

services from the Department of Behavioral Health (DBH), there was hope that his psychiatric conditions would be better supported. Unfortunately, he was promptly arrested for assault, and he sustained a serious physical injury during the episode. Despite the challenges of monitoring and advocating within the DBH system, we have continued to remain a constant in his life.

These stories demonstrate that there is no quick and easy solution to improving the lives of people with co-occurring intellectual disabilities and persistent mental health issues. As we have pointed out in many of our reports, the best chances for improvement rest with well-functioning teams who communicate, coordinate, and document as a cohesive unit. Quality Trust staff will continue to monitor, support, and advocate for everyone we meet to ensure they can live lives of dignity, meaning, and purpose.

10-Year Lookback/Comparison

The data below is a snapshot of data from this year compared to ten years ago.

- There were 1160 incidents in 2013 and 1150 in 2023.
- As is typical, the largest category of Serious Reportable Incidents was Unplanned Emergency Inpatient Hospitalizations for both years.
- In the 10 years between 2013 and 2023, the number of people receiving services grew by approximately 5%, from 2190 to approximately 2300.
- Ninety-two percent of people with whom we interacted in 2013 were between the ages of 21-50, while 59% of people we monitored in 2023 were between the ages of 21-50. This is most likely because our monitoring in 2013 was limited to people who were not former residents of Forest Haven.
- 2023 is consistent with 2013 in that most medical hospitalizations were related to pneumonia, aspiration, urinary tract infections, bowel impaction, and physical injuries.
- There were 34 deaths in 2013 and 41 in 2023.

Advocacy

There were twenty-nine (29) new referrals for advocacy during the year. This is a decrease of eight from the previous year. We anticipated a substantial increase in requests for advocacy in FY 2023 due to changes in eligibility requirements in the new legislation and for people requesting support in applying for the IFS waiver. As noted earlier, this did not happen as only one person requested support with applying for the IFS waiver.

The breakdown by referral source is as follows:

Referred by:

DDS	QT	Family/Friend	Outside Agency	Person	Provider
3	8	10	8	0	0

Outside agencies that referred people for advocacy:

- Iona Senior Services
- DC Public Schools

- Clover Leaf Wealth Strategies
- Children's Law Center
- Private attorney
- Findhelp.org

Requested outcomes:

DDA Application	Housing	Employment	Benefits	General Issues	Financial Issues
11	6	1	1	9	1

Outcomes met:

- Improved healthcare
- Residential move
- Access to housing
- DDS application approved
- Mediation within a team
- Benefits restored
- Autonomy
- Decision-making support
- In-home supports requested

The advocacy work at Quality Trust continues to primarily support people in gaining access to DDS services. Families and outside agencies often struggle with providing appropriate documentation, understanding their options, and communication between DDS intake staff and themselves.

Conclusion

After several delays, including a delay related to COVID, 2023 was the first year that all states throughout the country were expected to fully comply with the HCBS Settings Rule. As the Settings Rule made clear, development of a system of services and support based in professionals and providers making decisions for people with intellectual and developmental disabilities is an outdated paradigm. What we found is that new expectations for community-based services for people with disabilities and systemic developments for FY 2023 have yet to change the standard operating procedures of provider staff, service coordinators, clinical staff, and families. Too often we found top-down decision making in which outcomes not chosen by the person are dictated rather than developed in partnership with people with disabilities. Changes of this magnitude will take time.

Despite the best intentions of these new ground rules and expectations, too often our monitoring data demonstrated that people were not able to make meaningful choices about their most fundamental rights such as where they live and whom they live with. The continued practice of filling in vacancies creates a limited pool within which people are offered the options of where and with whom they live, which does not meet the spirit of the Settings Rule. People continue to have residential agreements with their providers, rather than leases with the housing

management, which retains control with providers over people's true independence. The challenging work of giving people methods to create wealth and real autonomy is still many years away.

In that way this year shines a light on where we need to go in the future. For some people who have never been offered true autonomy, this reality goes unheralded. They simply go about their day-to-day lives in the manner they always have. Some people, especially those who have entered the system in the past few years, however, exercise their choice by coming and going from their homes on a schedule and for reasons of their preference rather than that of providers, guardians, and government officials. In many cases our response is to call their choice a Serious Reportable Incident and label them a missing person rather than understanding the person's communicating of their basic civil rights.

To be clear, the District of Columbia has come a very long way in developing a rational and cohesive system of services and supports for people with developmental disabilities. Despite continued barriers as described in this report, there has also been considerable progress not only this year but over the lifetime of Quality Trust. Improvements to DDS's Incident Management and Service Coordination units have been significant as evidenced through data collection and individual stories. Far from sitting on a back burner waiting well past the required 45 days for completion, investigations are thorough and timely. Service Coordinators are better educated and trained, and both Service Coordinators and IMEU Investigators are much more adept at recognizing and reporting Serious Reportable Incidents.

However, the purpose of the HCBS Settings Rule was to question and upend the assumptions that have governed the provision of community-based supports. In that sense the system that has been created is now called on to reinvent itself. To give people more autonomy, government and providers must retain less. That change will be slow and difficult, but as we have for over twenty years, Quality Trust remains steadfast in our belief in the inherent dignity of everyone we meet. Since 2001, we have stood beside people with disabilities and advocated for people to live their best lives.

Appendix A
Random Monitoring Preliminary Data

General Data = 94

- 22/94 (23%) people were between the ages of 31-40, which was the largest age group represented
- 79/94 (84%) people received funding through the HCBS Waiver
- 43/94 (46%) people lived in supported living
- 22/94 (23%) people had in-home support in their natural home
- 26/94 (28%) people reported choosing their home
- 26/94 (28%) people reported choosing their roommate
- 13/94 (14%) people reported knowing how to request a new roommate
- 36/94 (38%) people received companion services during the day
- 35/94 (37%) people stayed home, retired, or spent their day without formal day support
- 12/94 (13%) people attended day habilitation
- 63/94 (67%) people reported being happy with the activities they participate in during the day

People Receiving Waiver Residential Support = 46

- 46/46 (100%) people who receive residential support from providers (Supported Living, Host Home, and Residential Habilitation) reported having private access to a phone
- 27/46 (80%) people living with residential support reported having privacy in their bedroom
- 31/46 (46%) people reported that they control their daily schedule
- 26/46 (57% people reported having control over their finances
- 17/46 (37%) people reported that they have access to their money without advance notice
- 22/22 (100%) people living in their natural home and families reported liking their support staff
- 17/22 (77%) staff working in a natural home demonstrated knowledge of the person they were supporting

People receiving ICF Residential Support = 14

- 6/14 (43%) were able to demonstrate that they liked their staff
- 5/14 (36%) were able to demonstrate that they liked their home
- 7/14 (50%) people had a BSP for behavioral support
- 4/14 (27%) had increased staffing of 1:1 or 2:1
- 4/14 (27%) of the person's Physician's Orders, Health Passports, and Health Care Management Plans had matching information
- 10/14 (71%) staff were trained in the person's HCMP
- 9/14 (64%) of the homes visited were clean
- 10/14 (71%) people had documented visits to the community of various sorts
- 8/14 (57%) staff had documented training on the person's goals and objectives

Day Supports = 59

- 17/59 (29%) people reported they were learning to ride public transportation
- 13/59 (22%) people formally worked on self-determination
- 15/59 (25%) people worked on developing relationships
- 19/59 (29%) people were formally working on community integration
- 3/59 (5%) people had a position where they contributed to the community through volunteering

Service Coordination = 94

- 88/94 (94%) DDS Service Coordinators completed a quarterly face to face monitoring tool
- 79/94 (84%) DDS Service Coordinators demonstrated that they made monthly contact
- 89/94 (94%) DDS Service Coordinators demonstrated knowledge of the person and what was important to them
- 88/94 (94%) DDS Service Coordinators were seen as advocates for the person's preferred outcomes based on their monitoring tools and MCIS notes

Conclusions

- 2/94 (2%) people had a Serious Reportable Incident generated by QT staff after monitoring
- 1/94 (1%) people monitored were referred for continued QT advocacy

Appendix B
[QT Nursing Monitoring]

Number of Psychiatric UEIH Hospitalizations = 100

- 88 (88%) had multiple incidents
- 67 (67%) had CPEP involvement
- 79 (79%) had police involvement

Number of Medical Hospitalizations = 304

- 163 (54%) were multiple visits
- 80 (27%) were hospitalized for the same reason
- 252 (83%) had nursing services provided
- 265 (88%) had Health and Wellness Nurse practitioners involved
- 33 (12%) needed f/u by QT

Number of Medical UEIH Follow-ups Completed = 61

Reason for Admission

- 4 (6%) – UTI
- 5 (7%) – Pneumonia
- 8 (11%) - Breathing problems
- 2 (3%) – constipation
- 7 (10%) – Seizure
- 1 (1%) - g-tube issues
- 3 (4%) – injury
- 3 (4%) – vomiting
- 1 (1%) – stroke
- 1 (1%) - heart attack
- 6 (8%) – sepsis
- 5 (7%) - person not acting like themselves
- 15 (21%) – N/A
- 11 (16%) - None of the above

*Note that some people had more than one reason

Type of Living Arrangement

- 9 (15%) – Natural Home
- 37 (61%) - Supported Living
- 12 (20%) - ICF
- 2 (3%) – Res Hab
- 1 (2%) – Nursing Home