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Fiscal Year 2024 Monitoring Summary

October 1, 2023 – September 30, 2024

Executive Summary

This report covers Quality Trust's monitoring and advocacy work during Fiscal Year (FY) 2024.

Quality Trust has four Quality Services Navigators who complete monitoring and advocacy on behalf of the approximately 2,500 people receiving services through the Department on Disability Services (DDS) Developmental Disabilities Administration (DDA). For the past two years, the Navigators have also interviewed people through the National Core Indicators (NCI) project. Our two nurses manage, triage, and follow up on all hospitalizations and long-term care placements. Our team works to ensure that people are free from harm, have the support they need to understand their rights, and make their own choices.

During this fiscal year, we began to implement a quality measurement process for use outside the District of Columbia called Dimensions of Support (DoS). DoS is based on our 20-year experience monitoring services and supports in the District and rooted in the principles of person-centered planning and thinking. DoS seeks to assist providers in their pursuit of providing high quality in the context of the many complicated regulatory requirements facing providers today. We hope to fully deploy DoS in FY 2025.

This report is based on data collected by our team. It focuses on the extent to which people experience true autonomy and have reliable healthcare, meaningful employment, and social involvement. Our analysis indicates most people enjoy limited autonomy related to where and with whom they live, and significantly less when it comes to employment. Very often, basic health and wellness supports remain elusive. In most cases the uneven supports around health and wellness do not place people in immediate jeopardy, but failure by providers and DDS Service Coordinators to ensure continuity of care does place people at significant risk.

Ongoing issues identified through this year's monitoring are:

- The current direct support professional (DSP) shortage limits people's options and choices and results in staff working multiple back-to-back shifts.
- Lack of consistent and routine training on nursing/medical supports and subsequent oversight by Qualified Intellectual Disabilities Professionals (QIDPs) and managers of DSPs undermines training outcomes leading to a lack of health and safety for many people in the system.

- Healthcare documents that are incomplete and don't capture the entire person place people at risk. DSPs are trained using these documents. They are meant to be a resource for staff. Staff cannot be expected to effectively carry out their vital roles when the documents they rely on are poorly written.

Since at least 2020, the demographic makeup of the people who receive services and supports is bifurcated. A small but growing number of people have a complex mix of support needs reflective of a non-institutionalized younger person. For them, connections to their friend groups are of paramount importance. Some of these people bring with them familiarity with recreational drug use and, sometimes, even addiction, as well as involvement in the criminal justice and behavioral health systems. At the same time, an ever-decreasing number of former residents of Forest Haven require significant medical/nursing and behavioral health support needs. These two dynamics come at a time of considerable programmatic change and fiscal scarcity both nationally and within the District of Columbia. In the wake of the COVID-19 pandemic, providers continue to be challenged to provide adequate numbers of appropriately trained DSPs to carry out the complex support needs and regulatory requirements within the Intellectual and Developmental Disabilities (IDD) system in the District.

As is always the case in times of profound change, alternative models of support and services will present themselves. The IDD system has been and will continue to shift away from reliance on provider-operated congregate living models to more semi and completely autonomous models. The Settings Rule of 2014 and the Centers for Medicare and Medicaid Services (CMS) State Medicaid Director Letter of July 2022 make clear that "Medicaid-funded HCBS [Home and Community-Based Services] that is intended to promote more common and consistent use within and across states of such nationally standardized quality measures in HCBS programs, create opportunities for CMS and states to have comparative quality data on HCBS programs, and drive improvement in quality of care and outcomes for people receiving HCBS." It is important for the stakeholder community in DC to set aside the differences that often fragment them and capitalize on new support models and sources of funding that will emerge.

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Introduction

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Our Approach

Quality Trust improves outcomes for people with IDD by:

- Triaging daily all serious reportable incidents reported to DDA such as neglect, abuse, exploitation, and unplanned hospitalizations
- Following up on every person deemed at risk through the triage process
- Following up for every person going into Long Term Acute Care (LTAC)
- Advocating for people going through the application process for services from DDS
- Advocating for people who have unmet needs
- Monitoring that includes meeting people, reviewing data, and interviewing those closest to them including family and Direct Support Professionals (DSPs)
- Meeting and interviewing 400 people through NCI
- Training and providing hands-on support for staff when QT nurses observe them doing something incorrectly during a monitoring visit

Our registered nurses play a vital role in monitoring through daily triage and supporting people involved in every unplanned or emergency inpatient hospitalization (UEIH). Our nurses do not provide hands-on care, rather they perform peer interactions with provider nurses and direct support staff. Their responsibilities include:

- **Comprehensive Monitoring**: Closely track the status of each UEIH, ensuring all follow-up needs are met.
- **On-Site Visits**: Visit individuals in hospitals, LTAC facilities, and homes to provide consistent oversight and support.
- **Thorough Medical Record Reviews**: Conduct in-depth reviews of medical records, verifying that everyone's health-care needs are accurately documented.
- **Interviews with Care Staff**: Communicate with agency nurses and staff, as well as hospital physicians and nurses, to evaluate the quality of care and identify opportunities for improvement.
- **Educational Guidance**: Train and educate agency staff on any of the areas needing attention, promoting high-quality, attentive care.
- **Safe Transitions to Home**: Ensure each person safely returns home, fully supported, and living their best, safest life.

In addition, our nurses collaborate closely with all members of planning teams to ensure that everyone shares the most current information in real time. They actively participate in discharge and team meetings ensuring their insights and recommendations are consistently shared across the care team.

National Core Indicators

National Core Indicators (NCI) is a national effort to use data gathered by interviews of people with lived experience to improve the performance of state developmental disability agencies. Quality Trust monitoring staff conducted the interviews for DC for the second year, increasing from 300 to 400 surveys. NCI is a significant commitment and has impacted Quality Trust's monitoring efforts. However, valuable information is obtained and allows DDS to compare its results to previous years, as well as to other states. Results can be viewed at https://idd.nationalcoreindicators.org/survey-reports-insights-2/.

FY2024 Random Monitoring

Monitoring Methodology

Our random sample monitoring in FY2024 concluded two years of monitoring implementation of the District's transition plan created to address a mandate from the Center for Medicare and Medicaid Services (CMS) "Settings Rule" that was originally unveiled in 2014, with an implementation date of 2020. Our sample was drawn from a list of 2,298 people receiving services and included 329 people. The Settings Rule required states to move their systems away from congregate models of mostly segregated service models to one offering more truly integrated models. For example, congregate segregated, so called "big box" day habilitation, models were to be phased out in favor of models that offered people opportunities for meaningful, integrated employment. Implementation was delayed from 2020 due to the pandemic, but states were expected to have fully developed plans in use by 2023. The District's transition plan was fully implemented in 2017. This is our second year using questions specifically formulated to help determine if the Settings Rule is effective in the everyday life of the people we meet.

Our monitoring tool for FY2024 was completed for a group of people chosen through a random sample that looked exclusively at the District's ability to provide meaningful opportunities for choice and autonomy.

Monitoring Results

True autonomy has always proven difficult to maintain. Only 49% of people we spoke to voiced that they chose their home. For those people, only 47% had the required

documentation demonstrating how that choice was made. 53% of people indicated they were able to choose their housemate, but quite often the process is an approval of a negotiation between the provider and DDS. For instance, someone was already living in a home and approved of a new person being referred to live with them. At the same time, the person being referred is quickly asked if they approve of the potential housemate. While there is a process for visitation, it is unrealistic to think that a person can make that decision after a meal and an overnight visit. We have heard numerous stories about how people initially liked a housemate upon meeting them, but then became upset when they learned about the characteristics of that person's personality. When it comes to autonomy in healthcare, there is even less choice. 57% of people received primary care from the physician their provider contracted with.

On a more positive note, 95% of people we met had their own bedroom, and 95% of people also reported having privacy when desired. This is a meaningful change from the days of larger group homes where multiple people shared the same room.

See Appendix A for more monitoring data.

FY2024 Reported Serious Reportable Incident (SRI) Breakdown

Incident Type	Number FY2024	Percentage of Total Incidents	Number FY2023	Percentage of Total Incidents	Number FY2022	Percentage of Total Incidents
Abuse	124	10%	139	12%	116	10%
Death	41	3%	41	4%	39	3%
Exploitation	78	6%	43	4%	55	5%
Missing person	45	4%	66	6%	89	7%
Neglect	309	25%	282	24%	358	30%
Serious Medication Error	18	1%	19	2%	27	2%
Serious Physical Injury	173	14%	130	11%	113	10%
Suicide Attempt	0	0%	6	<1%	9	1%
Unplanned Emergency or Inpatient Hospitalization	424	35%	404	35%	366	31%
UEIH/COVID-19	10	1%	11	<1%	9	1%

Other	3	<1%	9	<1%	3	<1%
Total	**1225**	**100%**	**1150**	**100%**	**1184**	**100%**

- Overall, the number of incidents increased by 75 or 6% from 2023.
- The increase of 35 exploitation incidents is primarily explained by one specific provider having many incidents after increased scrutiny by Incident Management Enforcement Unit (IMEU) staff of an initial exploitation incident.
- There was an increase in Neglect and Serious Physical Injury incidents.
- There was a decrease in Abuse and Missing Person incidents. The decline in missing person incidents is primarily due to the death of a person who had many incidents in the past.
- There was a decline in Suicide Attempts from six to zero. However, further research showed serious, ongoing psychiatric challenges for the individuals who made suicide attempts the previous year. One person had over 30 emergency room visits for psychiatric care and nine unplanned hospitalizations. Another person had 14 emergency room visits and five hospitalizations.
- We had expected to see a reduction in the number of UEIH incidents with the telehealth initiative being in effect for two years, but that did not happen. The telehealth initiative is voluntary, and it is our understanding that not many providers have chosen to participate. Further information is needed to determine whether those providers are seeing a reduction in UEIH incidents that could impact further decisions about the initiative.

SRI Triage

- DDS staff reported 156 incidents. This is consistent with last year when DDS reported 157 incidents. The largest reporting group was Service Coordination 64/157, with IMEU reporting 47/157 incidents.
- In abuse incidents, residential staff are alleged to have committed abuse 77% of the time, followed by day program staff at 9%.
- Five incidents were reported by Quality Trust staff in 2023 and again in 2024.
- Allegations of physical abuse occurred in 54% of abuse incidents.
- Sexual abuse made up 5% of abuse incidents. Everyone who alleged sexual abuse was contacted and referred to the DC Rape Crisis Center by Quality Trust.
- Police were called in only 6% of the allegations of physical abuse.
- 44% of neglect incidents were due to staffing issues. Examples of these incidents are staff leaving the home without another staff to take their place, failure of staff to show up for their shift, and staff leaving people alone in the community. Staff failing to cover 1:1 and 2:1 staffing was also an issue. The continued demand for more direct support staff is critical. We have observed staff working two full time shifts back-to-back and some staff working 15-hour

shifts without a break (see the death section). These long shifts put people at risk.
- 17% of neglect incidents were related to a person's healthcare.
- 35% of serious physical injuries were caused by a fall.
- Injury incidents of unknown origin decreased by half to 12% this year compared to 24% last year.
- 76% of missing person incidents involved people leaving their home to engage in activities of their choice whereas only 4% of people were unaccounted for. This points to the continuing failure of support teams to appropriately allow for people's preference to spend time without staff oversight and supervision. People did not return home as expected in only 18% of missing person incidents.

SRI Follow-Up

N=90

Because we are a small group of people advocating in a system of over 2,400 people, our daily triage process is our most reliable method for making decisions about how to best utilize our interventions. Determining who needs follow-up is a daily decision made by both the Nursing Coordinator and the Program Services Coordinator after reading the Serious Reportable Incidents received for the previous day. When looking at data from the last three years, it became clear that the people with the highest number of incidents often experience the most concerning outcomes. We reviewed incident data from 2022, 2023, and 2024 to follow individual people to determine how we might best anticipate negative outcomes in the future.

In FY2024 Quality Trust navigators and nurses followed up on 90 incidents of abuse, neglect, emergency hospitalizations, and serious physical injuries. Unplanned emergency hospitalizations were the largest category of follow up, with nurses completing 99% of the overall follow up.

Unplanned Emergency Inpatient Hospitalization

N=424

- 72% involved medical issues
- 28% involved psychiatric/behavioral issues
- 34% required continued advocacy from our team
- 94% of people were involved with the Health & Wellness unit within the Developmental Disabilities Administration[1]

[1] It is important to note that for UEIH incidents determined to be "routine" by QT's nurses, we may have closed our follow-up within 24 hours, and as a result, the Health & Wellness unit may not yet have been involved in the case.

UEIH In-Home Follow-Up completed

N=82

The follow-up process by our nurses for UEIH incidents is thorough and strategically designed to support high-risk individuals. Their follow-up focus is typically on people with repeated hospital visits, multiple chronic conditions, and/or severe, acute medical needs. After the SRI is triaged by the nurse coordinator, a QT nurse is assigned to conduct an in-home visit. This visit allows for a comprehensive review of the incident, ensuring all recommendations have been initiated and that essential medical equipment is both available and functional. Finally, it involves confirming that staff are trained on the Health Care Management Plan (HCMP) and briefed on any new medical concerns.

When training gaps are identified, our nurses coordinate with the agency's registered nurse (RN) or Qualified Intellectual Disabilities Professional (QIDP) to provide necessary training, supporting staff readiness and people's safety. This approach aims to minimize the risk of recurrent hospitalizations by upholding high standards of in-home care and providing personalized, continuous attention and support tailored to each person's unique needs.

Reason for Admission	**Number of people**
Pneumonia	13
Labs off/sent by physician	10
Breathing problem	09
Person not acting like themselves	08
Constipation/blockage	05
Seizure	05
Vomiting	05
UTI	04
Stroke	03
Injury	02
Sepsis	02
Cancer	01
None of the above	15

The high rate of hospital admissions for respiratory issues, such as breathing difficulties and pneumonia, underscores the vulnerability of people with IDD to these health challenges. Some specific risk factors associated with IDD, such as swallowing and aspiration difficulties, weakened immune systems, and mobility limitations, significantly contribute to respiratory complications. Mobility and posture challenges can diminish lung capacity and hinder people's ability to clear secretions, increasing pneumonia risks. Additionally, communication barriers can delay diagnosis, as individuals may

struggle to express symptoms early on, and chronic respiratory conditions create a predisposition to infections.

Caregiver dependence further emphasizes the need for specialized, attentive care, as trained caregivers play a crucial role in recognizing early signs of respiratory issues. In response, QT nurses are proactively educating caregivers and healthcare teams about these risks, which is essential for promoting preventive care measures and reducing hospital admissions. This proactive education helps ensure that caregivers are well-equipped to detect early symptoms and take preventive actions, supporting better health outcomes for individuals with IDD.

Psychiatric Hospitalizations

The data shows that a small group of people with IDD are hospitalized repeatedly for psychiatric issues. These psychiatric admissions make up 28% of all hospitalizations, with 67% requiring comprehensive psychiatric emergency program (CPEP) services. Police engage in 88% of these incidents; mostly to ensure safety. This elevated level of police involvement shows the need for dedicated support during crises and highlights the importance of DDS providers and police working together to manage these situations safely and effectively.

Analysis and Intervention to Address Recurrent Hospitalizations

The follow-up evaluations conducted by our nurses on 82 UEIH incidents revealed significant trends and challenges in managing high-risk individuals. Notably, 65% of these people experienced multiple admissions, with 39% repeatedly hospitalized for the same health condition. These findings underscore the critical need for consistent, targeted interventions to prevent recurring health crises, and highlight the need for effective documentation, communication, and coordination between nursing and non-nursing staff. Our reports continually point to this weakness in the provider community.

Note: The following care plan is an example of how an intervention could be structured for a person in a similar situation, but it is not based on an actual individual.

Care Plan for Jane:
Jane, a 54-year-old woman with developmental disabilities, has been hospitalized four times in the past six months due to urinary tract infections (UTIs).

1. **Hydration Strategy**: Staff are trained to offer Jane water or her preferred flavored beverages hourly during waking hours to ensure adequate hydration.
2. **Hygiene Protocol**: Staff receive training on proper perineal care techniques, emphasizing the importance of cleaning from front to back to reduce the risk of infection.

3. **Recognizing Signs and Symptoms**: Staff are educated to identify early indicators of a UTI, such as behavioral changes, cloudy urine, or increased agitation, enabling timely intervention.
4. **Bladder Health Support**: The agency nurse implements and trains staff on a bathroom schedule, prompting Jane to use the restroom every 2–4 hours. This practice minimizes the risk of bladder overfilling and potential infection.
5. **Medical Collaboration**: The agency nurse collaborates with Jane's primary care physician (PCP) to evaluate the appropriateness of a prophylactic regimen, such as low-dose antibiotics or urinary health supplements like cranberry extract.
6. **Monitoring and Feedback**: Weekly check-ins by the agency nurse include reviewing Jane's hydration and toileting logs, observing caregiver practices, and reinforcing training as needed.

Outcome:
Following the implementation of this care plan, Jane remains free of UTIs for six months, breaking the cycle of recurrent hospitalizations and significantly enhancing her quality of life.

Addressing Systemic Health Care Challenges

Inadequate documentation, combined with inconsistent staff training and high turnover, hinders the delivery of high-quality health care, and makes it challenging to create individualized, evidence-based care plans. Comprehensive records – such as Physician's Orders, Health Care Management Plans, and Health Passports – are crucial for ensuring that diagnoses, medications, and care recommendations are accurate, consistent, and effectively communicated. Reviews conducted by our nurses for the 2023–2024 period revealed that only 38% of the people we monitored or visited had thorough records, emphasizing the critical need for significant improvement in accurate documentation.

Addressing these gaps through enhanced documentation practices and robust, standardized staff training will be pivotal in improving patient outcomes, reducing readmission rates, and ensuring safety.

By focusing on both individualized interventions and systemic improvements, agency nurses play a crucial role in creating sustainable solutions that enhance care delivery and promote better health outcomes for individuals at risk.

Deaths

In fiscal year 2024, we lost 41 people. This is the same number of deaths we experienced in 2023. Outside of significant increase in deaths in 2020 and 2021during

the pandemic, there has been a slight but consistent increase in deaths over the last ten years (34 in 2015 to 41 this year, a 21% increase).

Year	Number of deaths
2015	34
2016	35
2017	38
2018	40
2019	36
2020	81
2021	57
2022	39
2023	41
2024	41

Many of the deaths this year fit the profile of previous years, e.g., expected deaths from causes that could not be prevented as determined by Columbus, the outside organization tasked with reviewing all deaths of people receiving service through DDS. That said, we did experience a small number of deaths that were unexpected. One person died after choking on a hot dog he wasn't supposed to have eaten. One person died in an out of state prison. A 44-year-old man who was severely malnourished died in his sleep on a cruise with his mother. A 75-year-old woman in good health was killed in a car accident while her DSP drove to get food.

Quality Trust reviews all Columbus Mortality Investigations to understand the individual concerns surrounding someone's death, but also to examine the systemic problems that persist.

When reviewing death investigations, there continue to be routine recommendations that provider nursing staff update or clarify information on physician's orders, Health Care Management Plans, and Health Passports so that they all contain the same information. Columbus consistently makes this recommendation "(*Provider name)* should ensure that the HCMP addresses all of the person's medical diagnoses as per the DDA Health and Wellness Standard 5: Health Care Management Plan." There is also a similar recommendation used for the Health Passport. Quality Trust has been making the same recommendations for several years. In addition, Columbus reports have included comments about the staffing shortage and how it plays out in staff working multiple shifts day after day, a serious and now persistent issue that we have also noted previously, but they have not included formal recommendations based on the problem.

- After reviewing 40 Columbus Mortality Investigations, the previously stated recommendation was made in 60% of the cases. It should be noted that this recommendation is not made for deaths in natural homes. This is consistent with

the finding of our nurses that only 38% of people monitored/visited by the nurses had thorough records.

- There were several investigations that mentioned staff working back-to-back shifts. Columbus made this statement “October 2, 2023, through February 23, 2024, staff person who worked with the decedent, for all her In-Home support hours, was the same staff person for 132 days out of the 146 days in that time period. This staff also worked fourteen-hour shifts for 11 days in that same time period. In addition, this staff person worked several twenty-four-hour shifts.”
- The staff who was working with one man was interviewed and acknowledged he worked the day program shift from 8am-3pm five days a week and then worked from 3-11 pm at the person’s home. This indicates a 15-hour shift of direct support with no breaks five days a week.

Three-Year Analysis of People with the Most Incidents

Person	2022	2023	2024
E	33 incidents – majority were missing person incidents where they left the home but also included abuse and neglect.	Arrested for indecent exposure, second degree assault, and fourth degree sexual assault. Sent to jail and not part of the DDS system.	Remains in jail
S	10 incidents – majority were psychiatric hospitalizations, but also included abuse, neglect, and missing person.	Voluntarily left the DDS system.	Out of the system
N	10 incidents of neglect, abuse, serious physical injury, and hospitalization. Has ongoing addiction issues and continues to have psychiatric concerns.	4 incidents – including reports of staff abuse and neglect.	5 incidents – while this is half of the number in 2022, the incidents are serious and have most recently included trying to light the apartment on fire by turning on all the gas and threatening staff with a knife.
R		15 Incidents including missing person, neglect, serious physical injury, and	Deceased

		unplanned hospitalization	
M		13 incidents including missing person and unplanned hospitalization	Deceased
S	3 incidents – included two psychiatric hospitalizations and one abuse incident.	10 incidents – continued to struggle with psychiatric issues.	20 incidents – including abuse, neglect, and psychiatric hospitalizations. One abuse incident involved one staff filming abuse by another staff.
I	2 incidents – experienced psychiatric issues.	6 incidents – more than double the number of incidents from the previous year.	21 incidents – more incidents than anyone else in the system, with the most recent involving breaking a lightbulb to cut herself.
A	11 incidents – included abuse, neglect, and psychiatric and medical hospitalizations.	9 incidents – of a similar in nature.	0 incidents – reported reasons for improvement noted below
R	Not on the high incident list	9 incidents – majority were for unplanned hospitalizations, but also included abuse, neglect, serious physical injury, and eventually death.	Deceased
B	2 incidents	13 incidents – the majority were for neglect but also included abuse and exploitation. It is reported that the person reports staff when upset about restrictions, which are related to drug use and overdosing.	2 incidents – QT researched what had changed and noted a plan for the person to receive money every month on an agreed upon schedule, have the intimate partner come to the home rather than go out, and consistent

			staffing. The person feels a greater sense of autonomy concerning the money.

When analyzing the data, death stands out as the most concerning outcome for people on the high-incident list, involving 36% of those listed. Not everyone who died was medically ill. While many people do pass away from complex medical conditions, there are other deaths that are more concerning. Two people on this list were battling physical illnesses that resulted in their death. One person who died had recently moved to a prison in Kentucky for a felony conviction here in the District. Another person was also incarcerated, struggled with substance abuse, and later died.

Some people also showed improvement, an outcome that deserves special focus. Understanding what contributes to their safety and well-being can help us identify effective strategies that might show promise for everyone. Two people stood out over the last two years. The number of incidents involving these two people significantly declined. We interviewed these people and their caregivers to understand what had happened to improve their lives. In one person's case staff reported better outcomes after a hospitalization at St. Elizabeths where medications were adjusted. The other person and her team reported improvement because she is receiving medical treatment which drained her energy. Where she had previously called 911 on a regular basis, she no longer makes those calls. Of further benefit was removal of a staff person she did not like.

SRI Follow-Up Stories

M.S.

On December 19, 2023, a Primary Care Physician (PCP) for M.S., a 78-year-old male with a history of aspiration pneumonia, ordered that all his fluids be thickened due to a risk of aspiration on thin liquids. During a routine home monitoring visit, our QT nurse observed M.S. seated at his desk with a non-thickened cup of Dunkin' Donuts coffee and a non-thickened glass of water placed directly in front of him.

Although staff claimed the fluids had been thickened by the previous shift, the QT nurse's inspection revealed that the drinks were not thickened as per the doctor's orders. The staff was immediately directed to remove the non-thickened fluids and properly thicken them under the QT nurse's supervision. The incident was promptly reported to DDS as a safety concern, and staff training on the critical importance of adhering to fluid thickening protocols was recommended to prevent similar occurrences in the future.

This incident underscores the need for ongoing vigilance and consistent staff training to ensure compliance with medical orders, particularly for individuals at substantial risk of aspiration, to mitigate further health complications.

W.J.

The follow-up conducted by our QT nurse on W.J., an 82-year-old man with a history of Ogilvie Syndrome, underscores the critical importance of personalized care and the role of familiarity in managing chronic medical conditions. During his recent respite stay, W.J. exhibited concerning symptoms – abdominal swelling, low oxygen levels, and an elevated heart rate – which necessitated hospitalization. While W.J.'s primary caregiver, a host family member, had been highly attuned to his non-verbal cues and had made every effort to communicate his unique needs to the respite staff, these efforts fell short. The staff, unfamiliar with W.J.'s specific care requirements, were unable to act swiftly enough, leading to his hospitalization.

The host family, who had opened their home to W.J. and his brother after losing their parents to COVID-19, exemplifies the value of a stable and compassionate caregiving environment. Their unwavering commitment to W.J. demonstrates the profound impact of a family, attentive environment on the health and well-being of individuals with complex medical needs. This case highlights the critical need for continuity of care and seamless communication between primary caregivers and respite staff. By fostering better collaboration and ensuring that caregivers are thoroughly informed of everyone's needs, preventable health crises can be avoided, leading to improved health outcomes.

Long-Term Acute Care (LTAC) Follow-Up

N=27

Our nurses perform a critical service by closely monitoring and supporting people in LTAC facilities. We conduct thorough follow-ups on all individuals with LTAC placements, monitoring their progress both during their stay in the LTAC facility and after their return home. The follow-up after discharge helps to bridge gaps in care, which can otherwise lead to readmissions, deteriorating health, or unsafe home environments. By staying actively involved from the initial placement through post-discharge, our nurses ensure that people receive the necessary equipment, up-to-date staff training, and all recommended care adjustments.

This kind of oversight is especially beneficial for people with complex health needs, as it reduces the risk of them being kept in LTACs beyond what is medically necessary. The proactive involvement of our nurses strengthens continuity of care, making transitions safer and more efficient for people – an essential approach, especially given that long-term care facilities can vary in quality and resources.

Our nurses completed 27 LTAC follow-ups during the period.

Reason for LTAC placement:

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

Reason for LTAC	Number of people
Wound care/G-tube wound care	12
Physical therapy/Occupational therapy	12
Trach care	06
Other skilled nursing	05
Antibiotic therapy	03

Wound Care: A Persistent Issue in LTAC Placements

Wounds, particularly pressure ulcers, are a recurring problem for many individuals with IDD, and they are frequently linked to inadequate care. Several factors contribute to the complexity of wound care in this population:

1. **Serious Illnesses:** Chronic health conditions, like infections or respiratory issues, can impede the body's ability to heal wounds effectively.
2. **Immobility:** Limited movement leads to increased vulnerability to pressure sores and skin breakdown.
3. **Weak Immune Systems:** Conditions such as diabetes or the use of medications that suppress immunity can significantly hinder wound healing and increase infection risks.
4. **Poor Nutrition:** Inadequate nutrition can delay wound recovery, as the body lacks essential nutrients needed for tissue repair.
5. **Underlying Health Issues:** Conditions like diabetes can affect circulation and slow down healing, making wounds harder to manage.
6. **Frequent Procedures:** Repeated medical procedures can leave people prone to infections, further complicating wound care management.

The chronic nature of wound care challenges, coupled with the risk of inadequate care, underscores the importance of proactive, consistent care and vigilance in preventing these issues from escalating.

As part of its LTAC follow-up, QT nurses ensure that all LTAC placements are in the least restrictive setting. However, nursing shortages[2] at LTACs can lead to delays in basic care, such as bathroom assistance and repositioning. These delays may lengthen hospital stays and increase risks of wound care needs, falls, and infections.

[2] Jacobs, A. (2024, February 29). *Nursing Home Staffing Shortages and Other Problems Persist, U.S. Report Says*. The New York Times. https://www.nytimes.com/2024/02/29/health/nursing-home-staffing-shortages-pandemic.html?searchResultPosition=1

Additionally, people have been discharged from rehabilitation without notifying DDS or Quality Trust, despite our nurses being involved in these cases. This lack of communication is concerning, as it may lead to unsafe home environments. Improving communication between LTACs, DDS, and Quality Trust could help prevent these issues. Staff shortages in LTACs continue to be a challenge post-COVID.[3]

LTAC Stories

1. A 77-year-old man, hospitalized for weakness and elevated ammonia levels, was transferred to a LTAC facility for strength rehabilitation. Due to dysphagia, he was prescribed strict feeding guidelines: no fluids during meals and water only 30 minutes after eating.

   During a visit, our QT nurse observed a staff member providing water during a meal, contrary to the prescribed protocol. She immediately intervened, educated the staff member on the correct procedure, and addressed the issue with the attending nurse and unit manager, who assured her the matter would be corrected.

   The following day, the nurse verified that the staff were adhering to the protocol. The incident was reported to DDS and the Maryland Department of Health. This case illustrates the critical role QT nurses play in safeguarding patient care and highlights how timely intervention and follow-up can prevent potentially life-threatening complications.

2. Our QT nurse was initially assigned to S.H. for an SRI follow-up after his hospitalization for low blood pressure, hypoxia, and a right buttock abscess. During the follow-up, the nurse identified that S.H. had four wounds, including a severe left buttock infection extending to the muscle. He had also been diagnosed with sepsis and pneumonia while hospitalized.

   During his hospitalization, S.H. developed some complications which required him to be discharged to a LTAC facility for continued treatment. While at the LTAC, the QT nurse raised serious concerns about his care, noting that S.H. was frequently left in the same position, appeared unclean, and had developed additional wounds. The nurse, in collaboration with S.H.'s sister, requested a transfer to a different facility. After the transfer was approved, S.H.'s sister contacted law enforcement to report concerns of neglect at the LTAC.

   Since his relocation, S.H. has shown significant improvement, with five of his wounds nearly healed, and he is now receiving nutritional supplements to

[3] American Health Care Association. (2024, March 5). *State of the Sector: Nursing Home Labor Staffing Shortages Persist Despite Unprecedented Efforts to Attract More Staff*. https://www.ahcancal.org/News-and-Communications/Press-Releases/Pages/State-Of-The-Sector-Nursing-Home-Staffing-Shortages-Persist-Despite-Unprecedented-Efforts-To-Attract-More-Staff-.aspx

support his recovery. The QT team continues to provide monthly follow-up to monitor his progress and ensure his care remains at an appropriate standard.

FY2024 Advocacy

- There were thirteen (13) referrals for advocacy in 2024.
- This is a significant decrease[4] from last year when we had 29 which was a decrease from 37 in 2022.

We anticipated a substantial increase in requests for advocacy in FY2023 and FY2024 as the new eligibility criteria created through the Developmental Disability Eligibility Reform Amendment Act of 2021 (DDERAA) took effect on October 1, 2022. That has not materialized yet, but we remain convinced that it will. We also expected a significant increase in demand for support through the Individual & Family Support (IFS) Medicaid Waiver, but only one person has requested support so far with applying for the IFS Waiver over the last two years.

Outside Referral Sources

- DDS
- Project ACTION!
- Department on Aging and Community Living (DACL)
- Families
- Providers

Outcomes met

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

Quality Trust Training

The QT Nursing Coordinator collaborated with Dr. Ronald Koshes to lead a training for QT staff on *Recognition and Treatment of Substance Use Disorders in the*

[4] Quality Trust has since learned that there were issues with our phone system for several months that affected people's ability to contact us. The problem has been resolved, and advocacy calls have already returned to normal levels, so we expect increased advocacy referrals in 2025.

Developmentally Disabled. This session focused on identifying signs of substance use in individuals with IDD and covered the latest, evidence-based treatment options. Dr. Koshes' expertise offered valuable guidance for improving care and support for this population.

QT thrives in offering specialized training on topics that address the intertwined medical and psychiatric needs of individuals with IDD. These targeted training courses not only enhance care quality but also equip staff with the knowledge to manage complex cases, supporting holistic, individualized care and improving outcomes.

People We Met in 2024

Jane

We met Jane because of concerns that arose from our daily triage process.

Jane had sustained a serious physical injury, a broken arm, of unknown origin. A Quality Services Navigator was assigned to complete follow-up. When the Navigator met Jane, they had to establish a method of communication as Jane did not use words to communicate. After establishing a yes or no head turn, the Navigator was able to discern that Jane was alleging that her residential nurse broke her arm. This was reported to the provider as an allegation of abuse by the nurse. Because the alleged incident occurred in an Intermediate Care Facility for Individuals with Intellectual Disability (ICF/ID), the DC Department of Health stepped in to investigate further. Without Quality Trust's belief that people can communicate without words, this severe injury and the alleged perpetrator might not have ever been investigated.

James

We met James through the advocacy process.

James was attempting to receive DDS services through the support of his grandmother. In preparing the application James and his grandmother took pride in and focused on his abilities rather than his needs related to his disability. When DDS had doubts about his eligibility, Quality Trust stepped in and supported the family in gathering essential documentation from doctors and schools to substantiate his diagnosis and his long-term support needs related to his disability. Within two months of QT intervention, James was approved for the IFS Waiver and is receiving in-home support.

Conclusion and Recommendations

Summary of Findings

- Advocacy requests were historically low at only 13. Most people were requesting support in completing the DDS application.

- Although a new group of people with developmental disabilities were potentially eligible for services last year through DDA, we did not see any change in our advocacy support requests.
- Self-directed services and support were offered for the first time last year. Again, we did not see any change in our advocacy requests for this support.
- People supported by DDS continue to show increased needs regarding children/family support, drug rehabilitation, legal issues, and psychiatric/behavioral supports.
- People continue to lack full autonomy.
- Healthcare continues to be a struggle for providers. Basic documentation for people is often inaccurate and incomplete.
- After two years, StationMD has not reduced the number of unplanned hospitalizations and may not be the best way to help sick people.
- While always noted, DSP training is often ineffective, and staff struggle to demonstrate the kinds of skills required.
- People who are experiencing higher numbers of incidents are at continued risk for poor outcomes unless major changes are implemented.

Conclusion

As the Setting Rule made clear, development of a system of services and supports based in professionals and providers making decisions for people with IDD is an outdated paradigm. New expectations for community-based services for people with disabilities and systemic developments for FY2023 should have been paired with a shift in thinking and practices from provider staff, service coordinators, clinical staff, and families to work in partnership with people with disabilities to create lives they desire.

Despite the new rules and expectations, our monitoring data did not demonstrate that people were able to make meaningful choices such as where they live and who they live with. The continued practice of filling vacancies allows little choice of where people live and who they live with. Many people continue to have occupancy agreements rather than actual leases, and when they purposely leave their home time after time, the answer continues to be a Serious Reportable Incident for a missing person rather than an understanding of the person's communication/behavior. The continued use of the Metropolitan Police Department for such incidents shows how the denial of someone's autonomy can result in excessive bureaucratic paperwork and the overuse of the MPD.

Quality Trust has not wavered from our belief in the inherent dignity of everyone we meet. For twenty years we have stood beside people with disabilities and attempted to educate and advocate for the improvement of systems and how people are supported to live their best lives.

Nursing Conclusion

Quality Trust nurses play a critical role in ensuring the health, safety, and well-being of individuals with complex medical and psychiatric needs. By combining vigilant oversight, targeted interventions, and robust collaboration with care teams, they effectively address both individual and systemic challenges.

The data highlights the vulnerability of individuals with IDD to medical and psychiatric crises, underscoring the need for ongoing advocacy and targeted training. Our nurses' commitment to addressing these needs is reflected in their continuous follow-ups, comprehensive interventions, and focus on systemic improvements to enhance care quality.

By emphasizing preventive care, strengthening communication among care teams, and championing patient-centered practices, QT nurses not only help to improve outcomes but also uphold the dignity and quality of life of the individuals they support. This commitment is evident in every aspect of their work, from in-home follow-ups to specialized training programs, making our nurses a cornerstone of quality care for high-risk populations.

Recommendations

1. Development of a curriculum that enables staff to support a diverse set of people requiring complex medical and psychiatric care. The current training modules required by DDS do not adequately address many facets that people within our system struggle with.
2. Development of a system of checks and balances to ensure direct support staff have retained their required training and are able to recall it in real time. The inability to demonstrate required training to any monitoring agency should result in inability to work until that person is retrained and can show competency.
3. New and enhanced training for DDS Service Coordinators and providers regarding how to initiate and process substance abuse interventions is sorely needed. In addition, DDS should consider a policy involving the use of Narcan.
4. Ongoing nursing training and supervision of direct support staff to reinforce collective understanding about complex conditions that affect our population such as seizures, bowel impaction, medication side effects, aspiration etc. Also introducing an improved signs and symptoms training that alerts staff to the seriousness of certain things they encounter and how to act accordingly, such as signs of aspiration pneumonia, a UTI, bowel impaction, etc.
5. Quality Trust will consider offering an advanced training series on issues not typically available in the routine IDD training tract. Possibilities could include training on substance abuse and intervention strategies, sexual abuse among people with IDD, and creative ways to support people that do not typically fall into the routine care provided to people without IDD.

Appendix A
Random Monitoring

General Data = 99

- 26/99 (26%) people were between the ages of 31-40, which was the largest age group represented
- 85/99 (86%) people received funding through the HCBS Waiver
- 56/99 (57%) people lived in supported living
- 22/99 (22%) people had in-home support in their natural home
- 31/99 (31%) people received companion services during the day
- 14/99 (14%) people attended day habilitation
- 30/99 (30%) people reported choosing their home
- 16/99 (16%) people reported choosing their roommate

People Receiving Waiver Residential Support = 59

- 59/59 (100%) people who receive residential support from providers (Supported Living, Host Home, and Residential Habilitation) reported having private access to a phone
- 22/59 (37%) people living with residential support reported having privacy in their bedroom
- 31/46 (67%) people reported that they control their daily schedule
- 27/59 (46%) people reported having control over their finances
- 27/59 (46%) 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

People receiving ICF Residential Supports = 10

- 8/10 (80%) people said they liked their staff, or they demonstrated to QT staff that they liked their staff
- 8/10 (80%) people said they liked their home, or they demonstrated to QT staff that they liked their home
- 6/10 (60%) people had a BSP for behavioral support
- 3/10 (30%) had increased staffing of 1:1 or 2:1
- 6/10 (60%) of the person's Physician's Orders, Health Passports and Health Care Management Plans had matching information
- 8/10 (80%) staff were trained in the person's HCMP
- 10/10 (100%) of the homes visited had appropriate food and supplies
- 4/10 (40%) people had documented visits to the community of various sorts
- 9/10 (90%) staff had documented training on the person's goals and objectives

Day Supports = 56

- 26/56 (46%) people reported they were learning to ride public transportation
- 22/56 (39%) people formally worked on self-determination
- 22/56 (39%) people worked on developing relationships
- 27/56 (48%) people were formally working on community integration
- 3/56 (5%) people had a position where they contributed to the community through volunteering

Service Coordination = 99

- 86/99 (87%) DDS Service Coordinators completed a quarterly face to face monitoring tool
- 81/99 (82%) DDS Service Coordinators demonstrated that they made monthly contact
- 90/99 (91%) DDS Service Coordinators demonstrated knowledge of the person and what was important to them
- 89/99 (90%) DDS Service Coordinators were seen as advocates for the person's preferred outcomes based on their monitoring tools and MCIS notes