

## **Fiscal Year 2022 Monitoring Summary**

**October 1, 2021 – September 30, 2022**

### **Executive Summary**

This report describes work completed by Quality Trust's monitoring and advocacy staff during Fiscal Year (FY) 2022. It addresses the decline in the spread of COVID-19 infections, the passage of landmark legislation changing eligibility requirements for services from the DC Developmental Disabilities Administration (DDA), and the analysis of data from our monitoring and advocacy on behalf of people with disabilities during the year. Other important issues that affected FY 2022 include renewal of DC's Home & Community Based Services (HCBS) Waiver for People with Intellectual and Developmental Disabilities (IDD Waiver), significant amendments to the HCBS Individual and Family Supports Waiver (IFS Waiver), the effects of continued staffing shortages, and reckoning with a "new normal" for supports and services beyond the disruptions experienced due to COVID-19 beginning in March of 2020.

The COVID-19 pandemic seems to be taking on endemic characteristics. The most serious outcomes - hospitalizations and deaths of both staff and those receiving services - have significantly decreased, and vaccination rates have reached into the 90%+ range for both staff and people with disabilities. In FY 2020, there were 81 deaths; in FY 2021 there were 57; and in FY 2022, 39 deaths were reported. Prior to FY 2020, the average number of deaths annually was approximately 36-38, so the number this year is in keeping with historical averages.

The Developmental Disability Eligibility Reform Amendment Act of 2021 (DDERAA) expands eligibility for DDA services to people with developmental disabilities, not just intellectual disabilities. The DDERAA ensures that people with developmental disabilities who have long-term support needs can access critical community-based services. The DDERAA also modified the definition of an intellectual disability so that it aligns with the current Diagnostic and Statistical Manual of Mental Disorders (DSM, 5th edition). Implementation of the DDERAA began on October 1, 2022, and the impact will unfold slowly as people now eligible apply for services. The new law will not directly impact people currently receiving services or people who have already been found eligible for services. However, as the legislation is being implemented, we will learn whether it brings positive changes to the lives of the approximately 2,300 people already supported by DDA. Other factors such as the availability of specific services needed by people and acute staffing shortages in critical areas are likely to have significant impact on people's lives and the effectiveness of the service system.

Quality Trust’s monitoring, review of Serious Reportable Incidents (SRIs), follow up on people placed in Long Term Acute Care (LTAC) settings, and general advocacy revealed several promising individual stories of rights enhancing supports and services. We also continued to encounter troubling disconnects involving coordination, communication, and documentation regarding nursing and programmatic services at several providers. These findings have persisted since FY 2020, although less significantly than prior to the onset of the pandemic. We are concerned that as we settle into a new “post-pandemic” normal, we are not seeing improvement in hiring and retaining the kinds of nursing staff needed, especially for people with complex medical and behavioral health support needs.

The passage of the DDERAA - something almost twenty years in the making - will usher in fundamental changes that will shape services in the decades ahead. It is not an overstatement to say that as FY 2023 begins, the system for providing supports and services to people with intellectual and developmental disabilities (IDD) in DC is being profoundly altered. The significant advancement realized in the new law through the collective efforts of people with disabilities, their families, government, providers, and community advocates demonstrated that positive change can be driven by a shared vision for the future. Our hope is that these collective efforts will be carried forward while the never-ending work of changing hearts and minds continues in FY 2023, and beyond.

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## **Introduction**

This report covers the work completed by Quality Trust's monitoring and advocacy staff during FY 2022. It first focuses on three overarching issues that helped define FY 2022: the decline in the spread of COVID-19 infections, updates to the District's Medicaid Waiver programs for people with IDD, and the passage of landmark legislation changing eligibility requirements for services from the DC Developmental Disabilities Administration (DDA). Next, the report addresses the effects of continued staffing shortages and reckoning with a "new normal" for supports and services beyond the disruptions experienced due to COVID-19 beginning in March of 2020. Finally, the approach and results of Quality Trust's monitoring and advocacy work are presented along with an analysis and recommendations for system improvements.

## **COVID-19: Year Three**

The COVID-19 pandemic hit with stunning and significant impacts for everyone in the community in mid-March 2020. Detailed attention to the effects of the pandemic on people with disabilities receiving services, the staff who supported them, and the many initiatives put in place by the DC Department on Disability Services (DDS) to combat and mitigate those effects was included in our last two Annual Reports. This report provides an update on the status of these supports and the continuing impact of this crisis on people supported by DDS/DDA.

According to DDS, in a posting dated December 8, 2022, since the onset of the pandemic in March 2020:

- 734 people receiving services from DDS have been diagnosed with COVID-19
- 144 of those people required hospitalization, with more than 80 of those occurring between March and May 2020
- New infections were at their highest in April 2020 with smaller increases from November 2020 to January 2021 and in December 2021 and July 2022
- Of the 177 total deaths of people supported by DDA during the period 2020-2022, only 38 have been confirmed to have been caused by complications from COVID-19
- 88% of people supported by DDA have received at least two vaccinations & 78% have received boosters
- 98% of provider staff have received at least two vaccinations & 71% have received a booster
- 98% of DDS staff have received at least two vaccinations & 90% have received a booster

Mayor Bowser lifted the indoor mask mandate a year ago, and this data demonstrates that the most disruptive and dangerous effects of the pandemic appear to have receded. This is great news for those who receive supports and their staff, but in many

very real ways, things have not returned to pre-pandemic normal. Most significantly, the landscape of day activities seems to have been permanently altered. This is not altogether bad as the options available to people with significant disabilities were limited. Transforming day supports away from “big box” day habilitation models was proving to be difficult, and COVID-19 accelerated the process. Over the last three years, home-based companion services have been used to provide people with opportunities for engagement while they could not leave their homes. This has subsequently transformed into an ongoing service model. Fully 83% of the people we monitored in FY 2022 said they enjoyed their day program services, though review of records indicated that in many instances activities provided lacked a clear connection to promoting the person’s visibility or meaningful connections to the communities in which they live.

In addition to the lack of meaningful day activities, volunteer activities, and paid work created by the pandemic, there is also a lack of experienced and well-trained staff involved in people’s lives. The defining advocacy issue for the DC Coalition of Providers has been problems with staffing for several years. The pandemic made a significant problem much worse. This issue is not local to DC and is noted as a significant challenge throughout the country. Difficulties recruiting, training, and retaining competent and consistent staff is challenging the entire field of supports for people with IDD.

### **FY 2023 HCBS Medicaid Waiver Changes**

The IDD and IFS Waivers are DC’s primary funding sources for community-based, long-term supports for people with IDD. While similar day and employment, as well as health and wellness services, are available under both Waivers, residential services outside a person’s natural or family home are only available under the IDD Waiver. There is also a \$75,000 annual limit on services available under the IFS Waiver. For individuals who want to manage their own services, self-direction is only available under the IFS Waiver.

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. In addition to the passage of a new law changing eligibility for services from DDA, these developments will significantly shift priorities in the District of Columbia’s system of supports for people with IDD in future years.

Changes to both the IDD and IFS Waivers include:

- Eligibility
  - Expands eligibility for services under the IDD and IFS Waivers to people with developmental disabilities who require long-term supports, not just people with intellectual disabilities
  - Changes the definition of intellectual disability to include onset through age 22, not age 18

- Assignment to the IDD or IFS Waiver
  - Previously, people would decide whether to apply to the IDD or IFS Waiver during the application process
  - Now, people will apply generally to DDS for services and DDS will assign the person to the IDD or IFS Waiver depending on which services are required to meet the needs of the person identified during the application process
- Every annual individual service plan (ISP) meeting will provide information about the availability of both the IDD and IFS Waivers
- Assistive Technology (AT)
  - Covers additional AT, such as virtual assistants, smart speakers, environmental control devices, and applications for prompting, guidance, and navigation
  - Removes the requirement for an AT assessment if the AT costs less than \$1,000
- Remote supports
  - Expands remote support services to additional types of service and for additional hours with a more clear rate structure, which may enable individuals to be more independent and less reliant on staff to be physically present to receive support
  - Remote supports will be available for the following services: behavioral supports, creative art therapies, day habilitation, employment readiness, family training services, occupational therapy, parenting supports, speech, hearing, and language, supported living, and some wellness services
- COVID-19 vaccination
  - Adds a COVID-19 vaccination requirement for DC healthcare workers<sup>1</sup> while assuring that an adequate provider pool will be maintained
- Supplemental payment
  - Direct support professionals (DSPs) will receive slight wage increases each year for five years starting in FY 2023, as authorized by DC legislation and the District's spending plan under the American Rescue Plan Act (ARPA)

Changes to the IDD Waiver include:

- Contribution to cost of care
  - Adds a requirement from DC law that all persons receiving residential services must contribute to the cost of those services, not just from public benefits such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), but from all sources of income
  - Costs include items such as rent, food, clothing, medical expenses, furniture, utilities, and other personal items and equipment

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<sup>1</sup> See 22 DCMR § B230.2.

- Contribution to the cost of care is required for people living in host homes, residential habilitation, and supported living settings
- Contributions may not exceed the current maximum SSI payment, minus \$100
- Supported living
  - Creates new tiers for reimbursement based on the level of awake, on-site staff support that a person needs

Changes to the IFS Waiver include:

- Participant-directed services (PDS)
  - Adds PDS so that the people receiving services under the IFS Waiver, or their representatives, have decision-making authority over and take direct responsibility for managing certain services
  - PDS is ideal for people who have a system of available supports
  - People who choose PDS will also have the assistance of a Support Broker to help with financial management and administrative support
  - PDS is available for in-home supports, individualized day supports, companion services, respite, and individual-directed goods and services
- Individual-directed goods and services (IDGS)
  - Adds IDGS for people using PDS
  - IDGS are services, equipment, or supplies not otherwise provided through the IFS Waiver or Medicaid State Plan that address a need in the person's ISP and promote inclusion in the community or safety in the person's home
  - IDGS are only available if the individual does not otherwise have the funds to purchase the good or service, and the good or service is not available through another source
  - Examples include fitness items or memberships, educational classes, cleaning services, food preparation services, and laundry services

These changes, along with federal requirements that seek to promote smaller, person-centered services, for the first time create opportunities for people receiving services to assert themselves as never before when negotiating with DDS and providers about the kinds of supports and services they need and want. Since Quality Trust began our work in the District in 2001, residential services have been provided in slightly modified models that were popular in the 1980's. In the early 2000's the Intermediate Care Facility for People with Intellectual and Developmental Disabilities (ICF/IDD) was widely used. In moving away from the facility model into services funded through the HCBS waiver, key elements from the ICF/IDD were retained. Amongst those was 24/7 awake overnight staffing. Simply put, it is difficult to reach the spirit of community-based living when even people who may not need such a high level of support receive this type of staffing, which is usually accompanied by a top down, one-size-fits-all support arrangement.

We are hopeful that the changes made to DC's waiver services will lead providers to adapt their business model in response to self-direction, increase use of remote supports and monitoring, increase the use of assistive technology, and allow for greater control and autonomy by people with developmental disabilities. More opportunity for autonomy and freedom to make real choices will ultimately result in better and more satisfying lives for people with developmental disabilities in DC.

### **Developmental Disability Eligibility Reform Amendment Act of 2021 (DDERAA)**

With the enactment of the DDERAA, the final piece of a process that began nearly twenty years earlier when stakeholders came together to modernize several different aspects of the system is in place. The major feature of this reform is broadening eligibility for services to people with a broad range of developmental disabilities instead of limiting services to people with a documented intellectual disability. Passage of the legislation ensures that people with developmental disabilities who have long-term support needs can access critical community-based services. The legislation establishes the definition of developmental disability that must be met for a person to be considered eligible for support services and modifies the definition of an intellectual disability to align it with the current Diagnostic and Statistical Manual of Mental Disorders (DSM, 5th edition). This new law will not impact people currently receiving services or people who have already been found eligible for services.

The provisions of this new bill took effect on October 1, 2022. The community of stakeholders eagerly awaits how the new eligibility determination process will play out in real time as more people seek support from DDA. People who had applied for services over the past three years and were denied services due to not having a diagnosis of intellectual disability were contacted about reapplying. It is anticipated that many of the services sought will be funded by the IFS Waiver. According to DDS leadership, there are currently enough vacancies to accommodate anticipated applicants, even though the exact number of new applicants is impossible to forecast.

### **Workforce Shortages and Use of Remote Supports**

Across the country, there is a crisis in supports for people with IDD, because of a lack of access to competent paid caregivers. The Arc of the United States shares on its website “[W]ith an average annual turnover rate of 45 percent, an average wage of \$10.72 an hour, and an average vacancy rate of 9 percent, the needs of people with disabilities, their families, and the workers themselves are not being met.”<sup>2</sup> While these are national figures and DC pay rates are slightly higher, DC has not been immune to the direct support professional (DSP) workforce crisis. Ian Paregol, Executive Director of the DC Coalition of Disability Service Providers is quoted in a 2021 Washington Post article,

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<sup>2</sup> The Arc of the United States, “Direct Support Professionals: Why It Matters.” Accessed at <https://thearc.org/policy-advocacy/direct-support-professionals/> on 12/29/22.

“The industry now is saddled with a *minimum wage* job where a prospective DSP [direct support professional] applicant is *more likely to contract COVID-19 than in virtually any other industry* coupled with a continually *ticking clock of attrition* (emphasis in the original).”<sup>3</sup>

An increasing number of people being eligible for and seeking access to long-term IDD services in DC along with chronic shortages of staff could lead to the development of waiting lists in a city that has not previously experienced this situation. However, most states have been contending with such lists for years, if not decades. What, then, will the post-COVID, workforce crisis, new eligibility for supports and services District of Columbia look like?

Two states have promoted one possible answer to meet the new reality by creating a growing role for remote supports and assistive technology. A report on Ohio Technology First, an initiative of the Ohio Department of Developmental Disabilities, notes that “Remote supports can be used by a variety of people, including those who have complex needs... Even if a person has restrictive measures, technology can be used to increase the person’s opportunities to live, learn, work, and thrive in their home and community.”<sup>4</sup> An Impact article describes several examples from two Minnesota providers on how they’ve used technology, including sensors and adapted call devices, to create opportunities for more independent living. The article describes how “technology keeps staff informed of when individuals come and go, take medications, are in or out of bed, have an activated smoke detector, and so forth. The technology is also used to provide reminders and prompts directly to the person, only involving staff if the matter isn’t resolved.”<sup>5</sup>

Use of these types of approaches will not only positively impact the workforce shortages currently confronting IDD providers, but as it reduces reliance on direct human support, it might also increase autonomy and freedom for some people receiving supports. In the District there is potential for broader use of technology and remote supports for recipients of services and supports in both HCBS waivers beginning in FY 2023.

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<sup>3</sup> Vargas, Theresa, “Help (desperately) wanted: One low-wage job has become harder to fill during the pandemic, despite the nation’s high unemployment rate,” The Washington Post, February 27, 2021. Accessed at [https://www.washingtonpost.com/local/help-desperately-wanted-one-low-wage-job-has-become-harder-to-fill-during-the-pandemic-despite-the-nations-high-unemployment-rate/2021/02/27/5f9d0b82-786f-11eb-948d-19472e683521\\_story.html](https://www.washingtonpost.com/local/help-desperately-wanted-one-low-wage-job-has-become-harder-to-fill-during-the-pandemic-despite-the-nations-high-unemployment-rate/2021/02/27/5f9d0b82-786f-11eb-948d-19472e683521_story.html) on 12/29/22.

<sup>4</sup> Ohio Department of Developmental Disabilities, “Technology First and the DSP Workforce Crisis: Ohio’s Future Paved By Technology,” August 2022. Accessed at [https://dodd.ohio.gov/wps/wcm/connect/gov/5bba191b-519b-4675-9219-483dc6474f43-od260Do](https://dodd.ohio.gov/wps/wcm/connect/gov/5bba191b-519b-4675-9219-483dc6474f43/DSP+Workforce+Crisis+Data+%282%29.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORSPACE.Z18_K9I401S01H7F40QBNU3SO1F56-5bba191b-519b-4675-9219-483dc6474f43-od260Do) on 12/29/22.

<sup>5</sup> Henry, SandraLee, “New Technology Means New Options for People Needing Supports: A Minnesota Story,” *Impact*, Volume 31, (Number 1), Winter/Spring 2018. Accessed at <https://ici.umn.edu/products/impact/311/Technology/#Technology> on 12/29/22.



## **FY2022 Monitoring and Advocacy Results**

### **Monitoring Methodology**

Our random sample monitoring in FY 2022 involved a follow-up on the themes we presented in our report titled, “Looking Back: A Collaborative Longitudinal Analysis of Data Impacting People in the Disability Service System over 10 Years, Examining Data and the District of Columbia’s Progress on Reform.” That report highlighted demographic trends affecting the IDD system between the years 2010-2020.

Specifically, the data showed that the number of older people - especially those who once lived at Forest Haven - was declining. New people entering the system are younger, and many present with complex behavioral health issues in addition to their developmental challenges. This group of younger people also have expectations of greater autonomy and independent decision-making.

This year’s monitoring sought to determine whether the types of services being offered by DDA and implemented by providers was changing to meet these demographic changes. The questions in our monitoring instrument primarily focused on issues of choice and autonomy. The secondary reason for choosing the questions centered on the District’s transition plan created to address the “Settings Rule,” a new mandate from the US Center for Medicare and Medicaid Services (CMS). The “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.

Rather than our statistically significant simple random sampling process, we chose to create two sub-samples; one included people who have been receiving supports through DDA for between four (4) and ten (10) years, while the other consisted of a group who have been receiving services for eleven (11) or more years. People represented in the first group consisted of 55% of the sample, while the longer-term service users made up 45%. Using this type of sub-sampling, while interesting for what it says about the people in the two groups, removes the predictive nature of our results. In that sense, this data cannot be generalized to the entire DDA system of approximately 2,300 people as a statistically significant sampling would.

Another challenge we faced was the lack of historical information included in many people’s ISP. When people are not able to tell us about their pasts, we must rely more heavily on their closest supporters and historical documentation for information. We encountered situations where the person was not able to tell us about their past, their staff were new to them, and we could not locate relevant historical information. That said, the data do provide insights into several issues involving not only choice and autonomy, but also the delivery of health care supports. Our monitoring tool for FY 2023’s random monitoring will look exclusively at the District’s ability to provide meaningful opportunities for choice and autonomy. We will also return to constructing a statistically significant random sample.

Our non-medical questions focused on the extent to which people exercised choice and autonomy regarding basic service characteristics such as where and with whom they live, what type of day activity they participate in, and how much control they enjoy over activities such as spending their own money and participating in community activities linked to their unique preferences. We wondered if there would be different answers for the folks who entered the system more recently. People were randomly assigned to be monitored. Monitoring was completed in person and online as requested by the person/family.

### **Random Monitoring: 10-Year Look Back**

N=126

We met 126 people through this monitoring process. The majority of people monitored had received services for less than 10 years and were under 29 years old, and a quarter of everyone either identified themselves or were identified by their circle of support as having autism. This is important because Quality Trust has advocated for years that the number of people in the system who have autism must be understood by DDS so that the uniquely tailored supports they require can be developed. In response DDS has indicated that they do not track such information so have no way of knowing how many people might require such services and supports. Most people came to DDS after aging out of school and have received services for at least 5 years.

While less than half the people we met chose their home, most reported liking their home. Only 22 people (17%) were employed and another 27 (21%) reported wanting to become employed. Autonomy in people's daily lives starts to shrink the more independence the activity requires. For example, 86% of people have a bank account, but only 69% have a bank card, and of those people, only 59% hold their own card.

Most people had family involvement, and many had friends. One (1) person was married, and three (3) people had children. Almost half the people had legal guardians. A small group of people were involved with the criminal justice system, and two (2) people were on probation at the time of the monitoring.

Consistent and accurate healthcare documents remain a problem. People receiving nursing services are expected to have current Physician's Orders, Health Care Management Plans (HCMPs), and Health Passports (HPs) that have matching diagnoses, medications, and recommended interventions. In all three categories, only between 30-39% of required documents were accurate. Most people had a current physical, but not as many had a current dental visit. The most utilized interventions were bowel movement protocols, fall precautions, and seizure protocols. Forty (40) percent of people were diagnosed as obese, and a quarter of the people we monitored had diabetes. This is a significant and concerning finding considering most people seen

were under the age of 29. Adding to the complexity of these issues, more than a quarter of the people interviewed reported refusing their healthcare recommendations.

The picture painted from the data we collected is of relatively young people, enjoying family and friends, who are most often unemployed. They are likely to be overweight, and many have diabetes. Healthcare data shows the lack of consistency referenced earlier: poor communication, coordination, and documentation, which necessarily compromises the effectiveness of supports and interventions. Autonomy seems to increase depending on how safe the choice is or how simple the process is to implement. It is possible that some people are speaking to us and exercising choice by refusing supports. It was not clear whether people had been adequately supported to make these choices in an informed way, or if the choice people made was a rejection of the provider’s proposed approach to support.

As noted earlier, the limitations of both our sampling, and our inability to get a better historical perspective of some of the people we monitored, leads us to present this data as informative about these 126 people but not as projective about the 2,300 people in the system. That said, there is much in here for DDS to examine.

See Appendix A for numbers/data.

**FY 2022 Serious Reportable Incident (SRI) Breakdown**

<b>Incident Type</b>	<b>Number of Incidents</b>	<b>Percentage of Total Incidents</b>	<b>Number FY 2021</b>	<b>Percentage FY 2021</b>	<b>Change from FY 2021 to FY 2022</b>
Abuse	116	10%	137	12%	-15%
Death	39	3%	61	5%	-34%
Exploitation	55	5%	45	4%	+22%
Missing person	89	7%	63	5%	+41%
Neglect	358	30%	219	19%	+63%
Repeated Use of Emergency Restraints	2	<1%	0	N/A	N/A
Serious Medication Error	27	2%	9	<1%	+200%
Serious Physical Injury	113	10%	117	10%	-3%
Suicide Attempt	9	1%	2	<1%	+300%
Unplanned Emergency or Inpatient Hospitalization	366	31%	476	41%	-23%
UEIH/COVID- 19	9	1%	26	2%	N/A

Use of Unapproved Restraints	2	<1%			
Other	3	<1%	2	<1%	None
<b>Total</b>	1188	100%	1157	100%	+3%

**Final Disposition of SRIs After Investigation**

N = 1042

Number Substantiated	226
Number Substantiated for Abuse/Neglect	62
<b>Total Substantiated</b>	<b>288</b>
<b>% Substantiated</b>	<b>28%</b>
Number Unsubstantiated	134
Number Resolved	442
<b>Total Unsubstantiated</b>	<b>576</b>
<b>% Unsubstantiated</b>	<b>55%</b>
Number Administratively Closed	91
Number Inconclusive	64
Number Blank	23
<b>Total No Conclusion</b>	<b>178</b>
<b>% No Conclusion</b>	<b>17%</b>

- Overall, the number of incidents was consistent with last year (three percent increase).
- There was a decrease in allegations of abuse (15%).
- There was a significant decrease in deaths (34%). Without a report from DDS addressing the non-COVID-19 deaths from last fiscal year, it's difficult to put this into context.
- There was a marked increase in Missing Person incidents (41%). This is attributed to changes in how the current policy is being implemented, e.g., many people aren't missing, but rather they leave without authorization. This also might reflect the increasing number of younger people in the system who regularly leave home without authorization, exercising their expected autonomy.
- There was a dramatic increase in the number of Neglect incidents (63%). This is attributed to staffing shortages leading to either no staff or under-trained staff in people's lives, as well as significant improvement in DDS IMEU investigators uncovering neglect.
- The same dynamic as that found with Neglect incidents is found in Serious Medication Errors (a 200% increase).
- There was a sizable increase in suicide attempts. It's possible, but not verified, that this is due to the more complex behavioral health diagnoses of newer arrivals in the DDS system.

- There was a noticeable decrease in unplanned hospitalizations. We hope, but have not yet been able to verify, that this is due to the newly introduced telehealth service which was put in place for that reason.
- Regarding the disposition of incident investigations, we see a continuation of previous years. Overall, of 1188 total incidents, 1042 were closed as of the time this report was completed.

In a positive development, the Incident Management Enforcement Unit (IMEU) initiated several new incidents during investigation of an initial incident, showing good scrutiny by DDS staff in their investigations. In addition, the IMEU drafted and distributed for comment new incident reporting policies and procedures, including improved definitions for neglect and abuse. The performance of the IMEU continues to be a strength in DDS' overall quality management strategy.

### **SRI Triage/Follow-Up**

N=1101

- Quality Trust triaged 1101/1188 SRIs.
- Quality Trust's triage process could not collect data on 9 COVID-19 incidents, and triage was not completed on 39 deaths.
- We completed **156** follow-up reviews due to concerns identified during the triage process.
  - We completed **40** reviews in the traditional manner, where a Community Services Navigator or nurse is assigned after the triage process, schedules a visit with the person, and completes follow-up based on the specific incident.
  - We completed **116** reviews using an expanded monitoring process. This process allowed a more encompassing assessment to be completed for people we had the most concerns about. This assessment looked at the overall supports provided to the person, and not just the incident and subsequent follow up.
- We also completed monitoring of **31** people deemed at risk with two specific providers.
- See Appendix B for numbers/data.

### **Standard Triage Follow-Up**

N=40

Abuse	Neglect	Exploitation	Serious Physical Injury	Unintended Emergency Inpatient Hospitalization	Psychiatric Hospitalization	Missing Persons
7 (18%)	14 (35%)	2 (5%)	10 (25%)	5 (13%)	1 (2%)	1 (2%)

Abuse:

- Sexual abuse: 3/7 (43%)
- 2/3 people had a rape kit completed and 2/3 were referred to DCRCC
- Physical abuse: 3/7 (43%)
- Police called 3/7 times
- 3/7 (43%) requested continued advocacy from Quality Trust

Neglect:

- 6/14 (43%) due to the environment
- 2/14 (14%) medical in nature
- 7/14 (50%) had a previous neglect incident
- 5/14 (36%) requested continued advocacy from Quality Trust

Exploitation:

- Alleged 2/2 times that residential staff robbed people of their money or items

Serious Physical Injury:

- 4/10 (40%) had a diagnosis that made injuries more likely (seizure etc.)
- 8/10 (80%) went to the hospital
  - 4/8 (50%) were admitted to the hospital
- 1/10 (10%) had injuries due to a behavioral episode
- 1/10 (10%) requested ongoing advocacy from Quality Trust

Unintended Emergency Inpatient Hospitalization:

- 4/5 had multiple hospitalizations
- 4/5 had hospitalizations from the same problem
- 2/5 required continued advocacy from Quality Trust

**Expanded Triage Assessment**

N=116

Abuse	Neglect	Exploitation	Serious Physical Injury	Unintended Emergency Inpatient Hospitalization	Psychiatric Hospitalization	Missing Persons
28 (24%)	24 (21%)	7 (6%)	23 (20%)	18 (16%)	5 (4%)	9 (8%)

Abuse:

- 13/28 (46%) involved verbal abuse
- 9/28 (32%) involved physical abuse
- 2/28 (7%) involved an allegation of sexual abuse
- 0 arrests despite 9 allegations of physical abuse and 2 allegations of sexual abuse
- 24/28 (86%) alleged that residential staff were abusive

Neglect:

- 16/24 (59%) due to staffing issues
- 2/24 (7%) due to environmental concerns
- 6/24 (22%) deemed medical in nature
- 19/24 (79%) alleged residential staff were negligent

Exploitation:

- 4/7 (57%) alleged that residential staff stole money or items from the person

Serious Physical Injury:

- 20/23 (87%) resulted in the person going to the hospital
  - 4/20 (20%) were admitted to the hospital
- 4/23 (20%) were injured during a behavioral episode

Unintended Emergency Inpatient Hospitalization:

- 10/18 (56%) had previous hospitalizations for similar medical issues
- 12/18 (67%) had their discharge recommendations followed
- 7/18 (39%) had a Health Management Care Plan, a Physician's Order, and a Health Passport that matched
- 14/18 (78%) had a Health Management Care Plan, a Physician's Order, and a Health Passport that were current

Psychiatric Hospitalization:

- 5/5 (71%) had a current Behavior Support Plan and quarterly psychiatric medication reviews
- 5/5 (71%) had increased staffing in place

Missing Persons:

- 3/9 (33%) reported they left home purposely to gain independence

General:

- 92/115 (80%) staff interviewed during the monitoring process were considered knowledgeable about the person and the incident being reviewed
- 94/116 (81%) DDS Service Coordinators were able to give an overview of the incident in question
- 88/116 (76%) DDS Service Coordinators acted after an incident was reported

The expanded triage process demonstrated that when we looked at people around specific incidents with a more in-depth tool, the data was in line with what our typical and provider triage process demonstrated, as well as our random monitoring assessments.

Residential staff are most often involved in an abuse, neglect, or exploitation incident. Despite 11 allegations of sexual and physical abuse and two people going to the hospital after an allegation of abuse, police were only contacted in four abuse incidents. When neglect was alleged, it most often involved the person not having the recommended staffing followed by neglect deemed to be medical in nature.

Providers continue to follow up with medical attention after a serious physical injury. However, people who had hospitalizations most often had poor quality or expired health documents in their home, (only 39% of people had matching documents that state the person's diagnosis, interventions, medications etc.). More than half the people we met had previous hospitalizations for the same condition and when discharged, recommendations were not followed 67% of the time. People with a psychiatric hospitalization (22% of all hospitalizations) were more likely to have the police called (61%) than to be seen at the Comprehensive Psychiatric Emergency Program (CPEP), and 11% of serious physical injuries were acquired during an incident involving the person's behavioral health needs.

### **Triage/Provider Follow-Up**

N=31

Thirty-one people were monitored from two residential agencies providing IDD Waiver supports after concerns became evident during our triage process, as well as from staff from the providers. Fourteen people were from one provider, and seventeen from the other. Both providers are approved through the HCBS waiver. Multiple problems were found in both organizations. As seen through the monitoring results listed below, our concerns were justified.



Staff could relate recommended interventions	Medical follow up was done in a timely manner	Specialty recommendations were followed up in a timely manner	Physician's Order accurate	Health Care Management Plan accurate	Health Passport accurate
14/31	16/31	12/31	10/31	19/31	6/31

Quality Trust reported these findings to the provider management and DDS. The response from DDS was prompt and included enhanced monitoring to help correct the situation. Quality Trust continued to support several people with issues uncovered during the monitoring process through advocacy. Together with DDS, many corrections were made, and the providers remained engaged with us during our continued involvement in people's lives. That said, persistent concerns continue. As we have noted, and our data had demonstrated for several years, communication, coordination, and documentation in far too many instances are poor and must improve if people are going to be free from potential harm.

### **Long-Term Acute Care (LTAC) Follow-Up**

N=25

Quality Trust meets each person placed into LTAC, reviews each placement, tracks people throughout the placement to ensure the identified outcome is being achieved, and conducts follow-up visits after discharge as necessary.

- 25/25 (100%) people had follow-up after a LTAC placement
- DDS reported 100 % of LTAC placements
- 72% (18/25) required nursing advocacy follow up after being discharged from a LTAC placement
- Two people died while at a LTAC facility or immediately upon discharge
- 65% (15/23) people 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.

<b>Reason for LTAC</b>	<b>Number of people</b>
PT/OT	22
Antibiotic therapy	2
Wound care/G-tube wound care	5
Vent weaning/respiratory care	2
Trach care	1

Cardiac care	1
G-tube care	1
Skilled nursing	4

Quality Trust nurses deemed all placements as the least restrictive setting.

### **Advocacy**

There were thirty-seven (37) new referrals received during the year. This is an increase of eleven from the last year, but still far below the number of requests for advocacy received prior to the onset of the pandemic. We anticipate a substantial increase in requests for advocacy in FY 2023 as the new eligibility legislation brings us people we have not met before.

The breakdown by referral source is as follows:

#### **Referred by:**

DDS	QT	Family/Friend	Outside Agency*	Person	Provider
7	11	12	3	2	2

\* Outside agencies that referred people were the US Department of Agriculture, Iona Senior Services, and Legal Counsel for the Elderly

#### **Requested outcomes:**

- DDS application support
- Concerns about nursing care/support for improving services
- Financial issues/benefits issues
- Decision-making support
- Residential moves/transitions
- Immigration support/residency
- Support after sexual violence
- Help with a roommate situation
- Behavioral support/psychiatric support
- Rights violations
- Neglectful provider services requiring follow up
- Need for in-home supports

#### **Outcomes met:**

Examples of outcomes included:

- DDA application support

- Medical follow up
- Behavioral issues resolved
- Psychiatric issues resolved
- Residential moves
- Assistance in resolving benefits issues
- Transition from LTAC back home
- Transition from mental hospital

The two most requested outcomes were support in the DDS application process and follow up after a Long-Term Acute Care (LTAC) placement/hospitalization and subsequent return home.

Twenty-five (25) people are receiving ongoing advocacy at the time of this report.

### Conclusion

To summarize the events that made 2022 a dynamic year in the development of a more mature and modern IDD system in the District:

- The post COVID-19 world is beginning to take shape as the pandemic recedes.
- A new group of people, those with developmental disabilities, are now potentially eligible for services through DDA, although people with intellectual disabilities will continue to make up the bulk of service recipients.
- The District will have two robust waivers through which to organize, monitor, and fund services and supports.
- Self-directed services and supports will be offered for the first time. They are likely to be popular for many people, as has been the case in other states where they have been in place for some time.
- The use of remote monitoring and assistive technology will become a key mechanism to expand autonomy and reduce reliance on direct human assistance.
- Although the IFS Waiver amendment and IDD Waiver renewal include funds for increased wages to DSPs, that funding is tied to ARPA funds that will eventually expire. Continuation of that funding will depend on future approval by the DC Mayor and City Council.
- Regardless of the targeted increases, the workforce crisis will continue. Lack of highly motivated, well-trained staff is a serious concern for all people with disabilities.

This report also highlights some of the many accomplishments and challenges that defined the system of services and supports for people with IDD in the District of Columbia in FY 2022. DDS deserves high marks for the many significant and important accomplishments realized this year. This is amplified because much of the work was completed during the COVID-19 pandemic. Implementation of new HCBS Medicaid

Waivers and introduction of a new law governing broader eligibility criteria will fundamentally change the system and shape how things will look and work in the future. Most critically, the introduction of self-directed services and increased use of remote monitoring and assistive technology have the potential for realigning the relationship between traditional providers and people seeking supports and services. Certainly, providers will be called upon to dramatically alter their current model of services provision to incorporate new technologies, meet new regulatory requirements, and respond to the changing expectations and needs of the people now seeking support.

As our monitoring data indicate, true autonomy is not universally available to everyone. It is currently conditioned on a whole host of factors and decisions usually made by someone other than the person with a disability. As the new Setting Rules make clear, development of a system of services and supports based in professionals and providers making decisions about the lives of people with intellectual and developmental disabilities is an outdated paradigm. New expectations for community-based services for people with disabilities must be about bolstering the ability of people with disabilities to access supports that enhance personal autonomy. Understanding and accepting the dignity of risk inherent in everyone's lives in a way that is respectful but still provides support for the person will be essential to achieving this goal. The systemic developments of FY 2023 must be paired with a shift in thinking and practice from provider staff, service coordinators, clinical staff, and families to work in partnership with people with disabilities to create lives they define as meaningful.

Since our inception, Quality Trust has not wavered from our belief in the inherent dignity of everyone we have met through our lay and legal advocacy and monitoring. Many of the building blocks needed to achieve better supports for people with disabilities are now in place. But building blocks don't create good lives. Achieving real change in the quality of opportunity and living for people with disabilities being supported in DC will require many people committed to standing beside people with disabilities as they pursue their life goals.

**Appendix A**  
**[Random Monitoring]**

- 44/126 (35%) people were between the ages of 18-29, which was the largest age group represented
- 31/126 (25%) people identified as having Autism
- 90/126 (71%) people received funding through the IDD Waiver
- 61/126 (48%) people had been receiving services for 5-10 years, which was the largest service length represented
- 28/126 (22%) people had been receiving services for 20 plus years, which was the second largest category
- 27/126 (21%) people reported applying to DDS after aging out of school
- 10/126 (8%) people reported applying to DDS after the death of a caretaker
- 26/126 (21%) people were Evans Class Members
- 55/126 (44%) people reported choosing their home
- 108/126 (86%) people reported liking their home
- 22/126 (18%) people were employed
- 36/126 (29%) attended a day program
- 27/126 (21%) reported wanting a job
- 108/126 (86%) reported having a bank account
  - 74/108 (69%) reported having a bank card
    - 44/74 (59%) reported they hold their own bank card
- 102/126 (81%) reported having a relationship with their family
- 86/126 (68%) reported that they have friends
- 1 person was married
- 3 people had children
- 42/126 (33%) reported that they wanted help with their relationships
- 54/126 (43%) people had guardians
- 9/126 (9%) have been involved with the criminal justice system
- 2/126 (2%) were on probation at the time of the monitoring
- 8/126 (6%) people were receiving support from the Department of Behavioral Health
- 46/126 (37%) people had a current behavior support plan (BSP)
- 41/126 (33%) people took psychotropic medication
- 9/126 (7%) people had a long-term psychiatric inpatient hospitalization
- 94/126 (75%) people walked without any supports
- 44/126 (35%) people had fall precautions in place
- 4/126 (3%) used a g-tube for nutrition
- 31/126 (25%) people had aspiration precautions in place
- 37/126 (29%) people had a diagnosed seizure disorder
- 9/126 (9%) people had a positioning protocol in place

- 57/126 (45%) people had a current bowel management plan in place
- 50/126 (40%) people were diagnosed with obesity
- 31/126 (25%) people were diagnosed with diabetes
- 117/126 (93%) people had a current physical
- 96/126 (76%) had a current dental visit
- 73/126 (60%) people were receiving nutrition supports
- 31/91 (35%) people had a current and accurate Health Passport
- 35/89 (39%) had a current and accurate Health Care Management Plan
- 27/89 (30%) had a current and accurate Physician's Order
- 11/126 (9%) people reported smoking tobacco
- 7/126 (6%) people reported drinking alcohol
- 5/126 (4%) people reported using Cannabis
- 32/110 (29%) people report refusing medical advice
- 17/126 (13%) people reported choosing their own doctor
- 29/126 (23%) people scheduled their own medical appointments
- 39/110 (35%) cooked their own food
- 86/126 (68%) people reported buying their own food either alone or with some staff support

**Appendix B**  
**[SRI Triage]**

- 4/108 (4%) people with an alleged abuse incident had police called
- 8/108 (9%) people with an alleged abuse incident had Adult Protective Services called
- 2/108 (2%) people went to the hospital due to abuse
- 335/337 (99%) incidents of neglect were alleged to be from provider staff
- 68/337 (20%) incidents of neglect were health-related
- 27/50 (54%) incidents of exploitation involved provider staff who stole money or possessions
- 3/50 (6%) incidents of exploitation had police contacted
- 11/108 (12%) people had a Serious Physical Injury due to a behavioral incident
- 4/108 (4%) received a Serious Physical Injury while having a seizure
- 60/342 (18%) people who had an Unintended Emergency Inpatient Hospitalizations were from natural homes
- 197/342 (58%) people who had an Unintended Emergency Inpatient Hospitalizations were from Supported Living
- 65/342 (19%) people who had an Unintended Emergency Inpatient Hospitalizations lived in an Intermediate Care Facility
- 295/342 (86%) people who had an Unintended Emergency Inpatient Hospitalization had nursing supports at home
- 127/342 (37%) people had previous hospitalizations within the last six months
- Breathing problems were listed most frequently on Serious Reportable Incidents for UEIH 22/268 (8%), with seizures next at 18 (7%), pneumonia at 13 (5%), g-tube-related issues at 11 (4%), and vomiting at 10 (4%)
- 75/342 (22%) people had incidents that were psychiatric in nature
  - 34/75 (45%) people with a psychiatric hospitalization went to CPEP
  - 46/75 (61%) had police called
- 46/89 (52%) people with Missing Person incidents had multiple incidents of going missing