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ANNUAL MONITORING REPORT FY 2021

Executive Summary

Fiscal Year 2020 will be remembered for the start of the Covid-19 pandemic. The disruptions to system reform efforts and other quality improvement activities were significant, and momentum for those efforts has yet to fully recover. Fiscal Year 2021 has been dominated by the challenges that remained as the Covid-19 pandemic continued to maintain its grip on services and supports for people with intellectual and other developmental disabilities in the District of Columbia.

Hospitalizations and deaths did not reach the highs seen in FY 2020. There were 81 deaths in FY 2020, but less than 35 were confirmed to be attributable to Covid. As we noted in our report last year, the non-Covid death increase was significant and requires urgent investigation. The 57 deaths this year mark a 30% decrease from last year but are still a significant increase from pre-pandemic levels. The importance of fully understanding the dynamics at play (and any trends) with non-Covid deaths cannot be understated. For instance, twenty-two former residents of Forest Haven were among the fifty-seven people who died in FY 2021 (39%), yet they represent only 16% of all people receiving services (378 of 2331). Without more specific data it is difficult to put into place the kinds of targeted interventions that will best support this aging population. Conversely, thirty-five people who never lived at Forest Haven also died in FY 2021. It would be easy to consider these people to be younger, but that is not the case. The median age is 52.

The primary cause for concern throughout the early and mid-year were substantial levels of staff infection which resulted in transmission to residents in several homes. As vaccinations became widely available in May 2021, there was renewed hope that the Covid pandemic could be halted in its' tracks. It quickly became evident that vaccination resistance was high among the pool of Direct Support Professionals (DSPs). Progress on this issue did not accelerate until the DC Department of Health issued emergency rulemaking on August 29th mandating that all direct care workers (including DSPs) receive vaccinations. Currently the overall rate of vaccination among DSPs is over 90%, but, as with so many aspects of services provided in the District, compliance rates vary among providers.

Our monitoring this year revealed significant under performance regarding the provision of routine health care support. While we cannot make statistically significant causal connections between poor nursing supports and a trend toward increased deaths, it is reasonable to accept that failures of nursing care can lead, in people with complex conditions, to serious but avoidable outcomes. What we see many times as the biggest shortcomings of health and nursing services and supports can be grouped into three categories: poor communication and documentation within nursing staff (LPN to RN) and between nursing staff and Direct Support Professionals., lack of training and awareness of people's important health related information on the part of LPNs and DSPs, and lack of urgency when crises do occur on the part of both nursing staff (both RNs and LPNs) and DSPs. The data in this report reveals that a combination of these factors, made worse by the disconnects presented by the Covid-19 pandemic has led to a worsening of preparedness and response by many providers. A fourth issue as the pandemic continues; the most troubling one of all is the lack of competent, trained staff available to provide vitally needed close contact personal services and supports. Simply put, unless there is a significant re-imagining of the provider-based community living model that has been in place for decades, there is little reason to expect these trends will be reversed. Given the changes contemplated in the New Settings Rules issued by CMS in 2014, the possible expansion of eligibility required in the proposed bill moving its way through the Council, and the ever-present constraints in DDS funding, a decoupling of the services people want from a provider only option should be considered. People rely on trained and motivated DSPs. Creating an option for them to obtain those supports while maintaining their own autonomy over how best to utilize them should be a goal in the District going forward. Implementing an option for self-direction is an urgent and important strategic issue which should be embraced and addressed by city leadership in collaboration with providers, advocates, and families. The makeup of the IDD system in DC is complicated by the fact that there is an increasing number of young people, and a decreasing number

of people who are older. The needs of the younger people now entering the system will need to become the focus for the system in the future. At the same time, the needs of older people cannot be minimized. Many questions remain to be addressed such as what the best course of action is to address both dynamics in a city whose healthcare system is rapidly changing. What we do know is that the important nexus between nursing supports, the role played by DSPs in conducting those supports, and the place this work occupies in the overall provision of healthcare in the District of Columbia in the time of Covid-19 must be thoroughly understood.

As we noted in our new report, *Looking Back: A Collaborative Analysis of Data Impacting People in the Disability Service System over 10 Years by Quality Trust*, there is a need to focus on what the data can tell us about the District of Columbia's progress on efforts to reform current models while proactively preparing for the future.

INTRODUCTION

Fiscal Year 2020 will be remembered for the start of the Covid-19 pandemic. The disruptions to system reform efforts and other quality improvement activities were significant, and momentum for those efforts has yet to fully recover. At the onset of the pandemic the District government, and The Department on Disability Services (DDS) specifically were quick to react; putting several different strategies in place to deal with the most damaging consequences created by the pandemic. Fiscal Year 2021 has been dominated by the challenges that remained as the Covid-19 pandemic continued to maintain its grip on services and supports for people with intellectual and other developmental disabilities in the District of Columbia. It was hoped that FY 2021 would bring renewed efforts toward ongoing improvements in the delivery of services to people with disabilities. While hospitalizations and deaths did not reach the highs seen in FY 2020, the colder weather of fall and winter forced people inside while another COVID variant surged. There were 81 deaths in FY 2020, but less than 35 were confirmed to be attributable to Covid. As we noted in our report last year, the non-Covid death increase was significant and requires urgent investigation. The 57 deaths this year mark a 30% decrease from last year but are still a significant increase from pre pandemic levels. The primary cause for concern throughout the year were substantial levels of staff infection which resulted in transmission to residents in several homes. As vaccinations became widely available in May 2021, there was renewed hope that the Covid pandemic could be halted in its tracks. It quickly became evident that vaccination resistance was high among the pool of Direct Support Professionals (DSPs). Progress on this issue did not accelerate until the DC Department of Health issued emergency rulemaking on August 29th mandating that all direct care workers (including DSPs) receive vaccinations. Currently the overall rate of vaccination among DSPs is over 90%, but, as with so many aspects of services provided in the District, compliance rates vary among providers.

The importance of fully understanding the dynamics at play (and any trends) with non-Covid deaths cannot be understated. For instance, twenty-two former residents of Forest Haven were among the fifty-seven people who died in FY 2021 (39%), yet they represent only 16% of all people receiving services (378 of 2331). Without more specific data it is difficult to put into place the kinds of targeted interventions that will best support this aging population. Conversely, thirty-five people who never lived at Forest Haven also died in FY 2021. It would be easy to consider these people to be younger, but that is not the case. The median age is 52. As we noted in our new report, *Looking Back: A Collaborative Analysis of Data Impacting People in the Disability Service System over 10 Years by Quality Trust*, there is a need to focus on what the data can tell us about the District of Columbia's progress on efforts to reform current models while proactively preparing for the future. The makeup of the IDD system in DC is complicated by the fact that there is an increasing number of young people, and a decreasing number of people who are older. The needs of the younger people now entering the system will need to become the focus for the system in the future. At the same time, the needs of older people cannot be minimized. Many questions remain to be addressed such as what the best course of action is to address both dynamics in a city whose healthcare system is rapidly changing. What we do know is that the important nexus between nursing supports, the role played by DSPs in conducting those supports, and the place this work occupies in the overall provision of healthcare in the District of Columbia in the time of Covid-19 must be thoroughly understood.

As we note at length in this report, our monitoring this year revealed significant under performance regarding the provision of routine health care support. While we cannot make statistically significant causal connections between poor nursing supports and a trend toward increased deaths, it is reasonable to accept that failures of nursing care can lead, in people with complex conditions, to serious but avoidable outcomes. What we see many times as the biggest shortcomings of health and wellbeing services and supports can be grouped into three categories: poor communication and documentation within nursing staff (LPN to RN) between nursing staff and Direct Support Professionals, lack of training and awareness of people's important health related information on the part of DSPs, and lack of urgency when crises do occur on the part of both nursing staff (both RNs and LPNs) and DSPs. The data in this report reveals that a combination of these factors, made worse by the disconnects presented by the

Covid-19 pandemic has led to a worsening of preparedness and response by many providers. A fourth issue as the pandemic continues; the most troubling one of all is the lack of competent, trained staff available to provide vitally needed close contact personal services and supports. Simply put, unless there is a significant re-imagining of the provider-based community living model that has been in place for decades, there is little reason to expect these trends will be reversed. Given the changes contemplated in the New Settings Rules issued by CMS in 2014, the possible expansion of eligibility required in the proposed bill moving its way through the Council, and the ever-present constraints in DDS funding, a decoupling of the services people want from a provider only option should be considered. People rely on trained and motivated DSPs. Creating an option for them to obtain those supports while maintaining their own autonomy over how best to utilize them should be a goal in the District going forward. Implementing an option for self-direction is an urgent and important strategic issue which should be embraced and addressed by city leadership in collaboration with providers, advocates, and families.

Returning to anything like pre pandemic normal is still far off into the future. Not only because of Covid-19, but also as noted above changes initiated by CMS. The concept of day programing as it existed pre-Covid is over and will not be returning. This is precisely why now is the right time to begin a transformation initiative. Funding for activities provided in buildings where people with IDD are segregated apart from people who do not have disabilities will no longer be eligible for Medicaid funding. If staffing shortages are a characteristic of the post-pandemic landscape rather than a short-term factor to be survived, new models of community living, and day activity support will be needed. As we all know, the pandemic is still a critical concern as this report is completed. The struggle to create a system that recognizes the unique character of people receiving services as we come out of the pandemic presents serious challenges. It can however also create new opportunities to finally better balance services away from top down, provider owned to something more cooperative and complementary of people with disabilities and their families. As we have noted in previous reports, the negotiation between people with disabilities and their families, providers and government must be fundamentally altered to result in greater control by people who use services.

While there is ample reason to be concerned about the future of services as we start a new fiscal year, there is also the potential for significant and fundamental restructuring. Those are the kinds of changes that CMS was hoping to achieve when the New Settings Rules were proposed in 2014. The approved HCBS Individual & Family Support waiver creates a mechanism to begin the process if DDS can assert the kind of leadership necessary to drive real change. To this point, DDS leadership has not demonstrated willingness to boldly lead this type of fundamental change. The new Individual and Family Supports (IFS) Waiver could allow District residents with intellectual and developmental disabilities (IDD) who live either in their own home or with family or friends, “to receive HCBS services and supports tailored to their specific needs.” This should enable people to “leverage supports from family or friends so they will not need to rely on traditional residential services” but is not currently being accessed as envisioned. The pandemic has also created an opening for a dramatic rise in the use of technology by and with people with disabilities. If these two shifts were fully realized, it would create significant momentum for shifting the system to one that is driven by the needs of the people served.

This report describes Quality Trust’s efforts to ensure the adequacy of services and supports for people supported by the District of Columbia’s developmental disabilities system during what has been an unprecedented now second Fiscal Year consumed by the Covid-19 pandemic. Our monitoring team, which has returned to in person monitoring has nonetheless incorporated many of the lessons learned through our virtual monitoring and will be integrating these adaptations into our monitoring protocols going forward.

October 1, 2020-September 30, 2021

Advocacy

There were twenty-four new referrals received during this year. The breakdown by referral source is as follows:

Referred by

DDS	QT	Family/Friend	RSA	School	Provider
6	6	9	1	1	1

Requested outcomes:

- Medical follow up
- Enrollment in reading class
- Help getting driver's license
- Help with school issues
- Financial issues
- Help with DDS application
- Decision making support
- Behavioral and psychiatric support

Outcomes met:

Fifty-seven outcomes met

Examples of outcomes included:

- Medical follow up
- Enrollment in classes
- Adaptive equipment secured
- Assistive devices secured
- Stolen money reimbursed
- Decision making supports put into place
- Behavioral issues resolved
- Psychiatric issues resolved
- Residential move
- Change in day activities
- Increased community integration
- Assistance in securing Medicaid waiver services

Barriers:

Twelve people were closed without an outcome being met. Three people died and nine people did not respond or participate.

Ongoing Advocacy

There are eighteen people whose outcomes was not met in 2021. They will continue with advocacy supports into the next quarter.

SRI Follow Up/Triage 10/01/20-5/30/21

487 non-health related incidents of were reviewed and triaged for further intervention as needed. The breakdown of these incidents by category is below. As a result, further review and follow-up was conducted for 15 people.

Type of incident	Number
Neglect	178 (37%)
Abuse	112 (37%)
Exploitation	36 (7%)
Serious physical injury	99 (20%)
Missing person	54 (11%)
Other	8 (2%)

- 165 (34%) people had a previous serious reportable incident in the last 6 months
- In abuse cases, the police were called on 12/112 incidents, only 11% of the time
- There were ninety-nine serious physical injuries. 15/99 were due to a behavioral incident. Of those fifteen people, eleven had a current BSP, and 7/15 had an increased staffing pattern (1:1 or 2:1)
- 4/178 incidents of neglect were alleged to be family. 171/178 incidents of neglect were alleged to be by provider staff
- 49/178 were deemed to be medical neglect

Long Term Acute Care follow up

Quality Trust receives notice of all placements to Long Term Acute Care Facilities (LTAC) for people supported by DDA. DDS reported 100% of LTAC placements as required, although there was a delay for one person. The LTAC date was January 8, 2021, but QT did not receive notice until June 25, 2021. These placements are typically made for people with needs for more intensive health care monitoring and rehabilitation than can be provided in the typical home setting. Quality Trust reviews each placement, tracks people to ensure the identified outcome is being achieved, and conducts follow-up as needed. Thirty-one (31) people had follow-up after a LTAC placement.

Reason for LTAC placement

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

Reason for placement	Numbers
Ventilator weaning	2
Occupational or physical therapy	13
IV antibiotics	4

Quality Trust Nurses deemed all placements as the least restrictive setting. One person died while in LTAC after having a bacterial infection (respiratory). Everyone who was discharged had what they needed at home except one person who needed supports for his family's shower. The QT nurse continued to support him until this was accomplished.

Random Monitoring

Random monitoring was completed by identifying the population as everyone who receives services from DDS and does not live in a natural home. People are randomly assigned to be monitored and all monitoring was completed virtually due to Covid-19 precautions being in place. Seventy-seven (77) people were included in this sample.

Where people lived

Type of funding/home	Number
Intermediate Care Facility	10 (13%)
Residential Habilitation	6 (8%)
Supported Living	40 (52%)
Natural	17 (22%)
Host Home	4 (5%)

Their Ages:

Age group	Number
21-30	18 (23%)
31-40	11 (14%)
41-50	10 (13%)
51-60	18 (23%)
61-70	11 (14%)
71-80	7 (9%)
81 plus	2 (3%)

Issues identified during random monitoring

- ISP (including all assessments) 4/77 (3 %)
- Goals and objectives 5/77 (3 %)
- Data collection (ABC, all health interventions, objectives, etc.) poor or missing documentation. 4/77 (3 %)
- Choice & Autonomy 8/77 (5 %)
- Healthcare 32/77 (21 %)
- Day programming/work/school 3/77 (2 %)
- Healthcare (including HCMP, staff training, documentation, clinical services, nursing supports, etc.) 45/77 (29 %)
- Behavioral Health (Plan development, RCRC approval, Psych med reviews, etc.) 9/77 (6 %)
- Unmet goals/desires of the person 5/77 (3%)
- Environment 10/77 (7 %)
- Adaptive Equipment (availability, working condition, being utilized correctly, etc.) 4/77 (3 %)
- Service Coordination (Lack of follow up of identified needs, visitation, and monitoring tools, etc.) 5/77 (3 %)
- Provider issues (list day & residential. Staff training, staffing, etc.)15/77 (10 %)
- Transportation 4/77 (3 %)

What people reported they wanted and did not have:
34/77 (44%) people were able to answer the question themselves.

What they want and don't have	Number
A job	6
To go back to work	3

To go back to day program	5
To go out into the community more	6
To go to church	2
A high school diploma	1
A driver's License	1
A learner's permit	1
Their own apartment	1
To see their boyfriend	1

Covid-19 Monitoring

Twenty-nine (29) people were randomly asked about their Covid-19 precautions to determine if staff and people supported felt educated about Covid-19 and had appropriate supplies and supports.

People Supported:
24/29 83% stated that they felt well.
13/29 (45%) reported that they knew who to tell if they felt sick.
21/29 (72%) reported that they knew about the signs of Covid-19.

Staff:
27/29 (93%) stated that they had their temperature checked upon starting their shift.
29/29 (100%) stated they had been trained about Covid-19.

Concentrated monitoring

In the spring of 2021, the Quality Trust initiated a healthcare review of a provider we noted several deaths and other incidents (including neglect) that were related to healthcare and hospitalizations. A review tool was developed containing eighteen (18) items addressing basic health care supports that should be available to all people. The two Quality Trust nurses selected a sample of people, completed a data review, and interviewed Direct Support Staff and provider Nurses.

Upon completion of the review for the first provider, we decided to expand our focused review of health care support practices to include samples from other providers to determine if similar gaps in service delivery found were present for people supported by other providers. Additional providers were selected based on concerns we identified during our daily review and triage of incidents that is a critical part of our ongoing monitoring at Quality Trust. Reviews were completed for a total of five (5) residential providers. The questions asked and raw data collected are included in Appendix 1 at the end of this report.

While all providers (75% or better) met the expectation for a current health passport, annual physical and nursing evaluation, issues with the accuracy and consistency of data throughout these and other health related documents were not found. The results for all providers fell below 60% for four (4) questions addressing whether there was accurate and current information contained in the critical health care documents for each person. These inconsistences in documentation can and do lead to poor communication of health priorities and effective coordination of effort across all people providing support to the person.

Review of Death Investigations

Over the past two years deaths have increased by a statistically significant degree when compared with prior trends. As we noted in our annual report last year, this is over and beyond the impact of Covid 19. While this year's fifty-seven deaths are lower than last year (81), it marks two years of notable increase.

During FY 2019-2020, we had become increasingly uncomfortable with the oversight of death investigations as conducted by the Mortality Review Committee. As a member of this body during that time, we consistently voiced our concerns and presented information we believed had either not been considered or had been dismissed as immaterial to the final outcomes of the investigations completed by the external contractor, the Columbus Organization. Failing to persuade the committee to change course we decided to end our participation. This was not a decision taken lightly, but we did not want to convey the impression by our participation that we agreed with the committee process and the final decisions reported by the committee.

As an alternative strategy to review the quality and comprehensiveness of death investigations, we engaged the services of a nurse who has decades of experience providing direct supports, advising state IDD systems leadership, and participating in death investigations in a state facility. We chose two people to review. One person was someone we had known for several years who died in April of 2020, as the pandemic was beginning to hit hard, but who did not die of Covid-19. The other person who died at the same time was known to have died of Covid-19. Given the substantial concerns we had involving nursing supports that are detailed earlier in this report, it also seemed a logic analytical extension to review deaths as well. Appendix 2 contains information and conclusions regarding the two deaths that were reviewed, and the process that was used in this review is described below.

A guiding document was designed to review information from the Columbus Report and other information available to Quality Trust such as Monitoring Tools completed by Service Coordinators, and such information we received from providers upon request. The reviewer considered consistent health care information essential to health maintenance and preventative care for persons with differing disabilities. This reviewer focused attention on the following three factors:

Section 1: Pre-existing Medical Conditions

Section 2: Risk Factors

Section 3: Home Management

The independent review of these two deaths confirmed for us what we had already identified as an ongoing concern. In many instances the Columbus investigations contain conflicting information, leave out critical information, and; of most concern fail to provide the thorough and rigorous analysis they would need to help identify and understand the causes of specific deaths to recommend measures that lessen the chances for future similar deaths. It is a significant threat to the overall quality management scheme in the District's IDD system that input and oversight by the MRC (Mortality Review Committee) committee has been unable to compel better investigations from its contractor. While we recognize this is a limited review, we hope the work highlighted here will spark a debate within DDS about ways to improve this process going forward.

SRI Follow Up Monitoring

Starting in June 2021, Quality Trust monitoring staff started a new monitoring assignment based on formal follow up of Serious Reportable Incidents. As Covid-19 continued to present challenges to in home visits, we explored this option of follow up that allowed us to monitor people virtually. One hundred nine (109) people were reviewed from June 2021-September 2021

Reviews were completed through record review on the DDS electronic database (MCIS), the provider electronic database (Therap), and individual interviews of people using various apps such as Facetime and What's App. Phone interviews were also completed with select DDS Service Coordinators.

Type and Number of Serious Reportable Incidents Reviewed

Type of Incident	Number Reviewed
Abuse	27
Neglect	25
SPI	21
UEIH Medical	13
UEIH Psychiatric	5
MP	9
Exploitation	7
Other	2

The providers who had the most visits

Provider	How many people reviewed
Innovative Life Solutions (ILS)	7
Wholistic Services	6
Frontline Community Services	5
Volunteers of America (VOA)	5
Total Care Services, Inc.	5
Community Multi-Services (CMS)	4
Multi-Therapeutic Services (MTS)	4
St. John's Community Services (SJCS)	4

The new format for following up on serious reportable incidents yielded a much larger sample than what we would typically complete. In 2020 we followed up on thirty-three serious reportable incidents. In 2021 we completed 109 follow ups. Although we met more people this year, we did not have as many referrals from continued advocacy. A total of eighteen (18) people were referred for ongoing advocacy. In 2020 we continued advocacy with 21% of the people we met through SRI follow up (7/33). In 2021 we referred 17% (18/109). The new monitoring process was much more involved, and Quality Trust Quality Service Navigators had the opportunity to correct certain problems during the actual process of monitoring. Our previous follow up was limited to the incident in question and was traditionally done in one visit. Navigators will continue to follow up on serious reportable incidents in this same manner going forward into 2022.

REVIEW AND ANALYSIS OF SERIOUS REPORTABLE INCIDENTS BY QUARTER

Incidents

In FY 2021, there were 1048 incidents recorded from 576 people who receive services through DDS. The number of incidents increased over the quarters in 2021 even though the number of people decreased. In the first quarter, 179 people experienced 235 incidents whereas only 111 people faced 274 incidents in the fourth quarter of 2021.

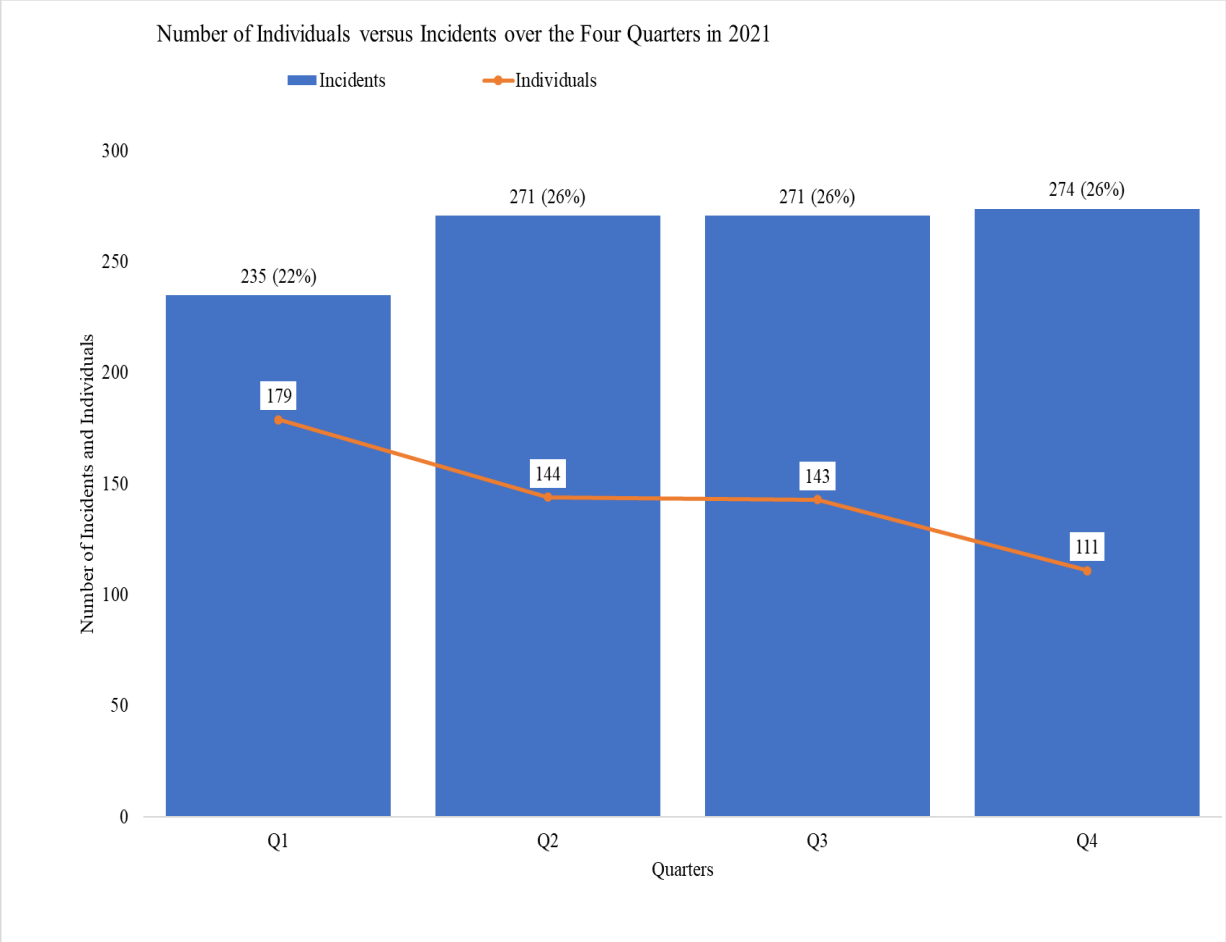


Figure 1. The number of people versus their incidents

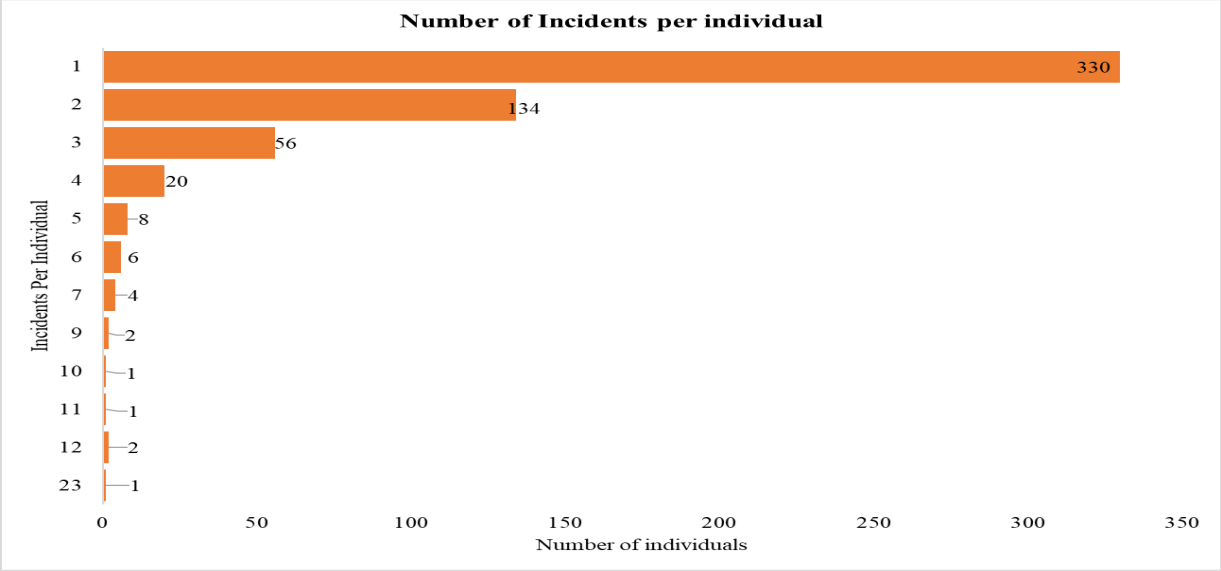


Figure 2. The number of incidents per person

Figure 2 displays the number of incidents per person. For example, one person had 23 incidents throughout the year. Thirteen (13) incidents was the second highest number of incidents experienced by a single person. Most people experiencing incidents however, 330 (57%) experienced only a single incident throughout the year.

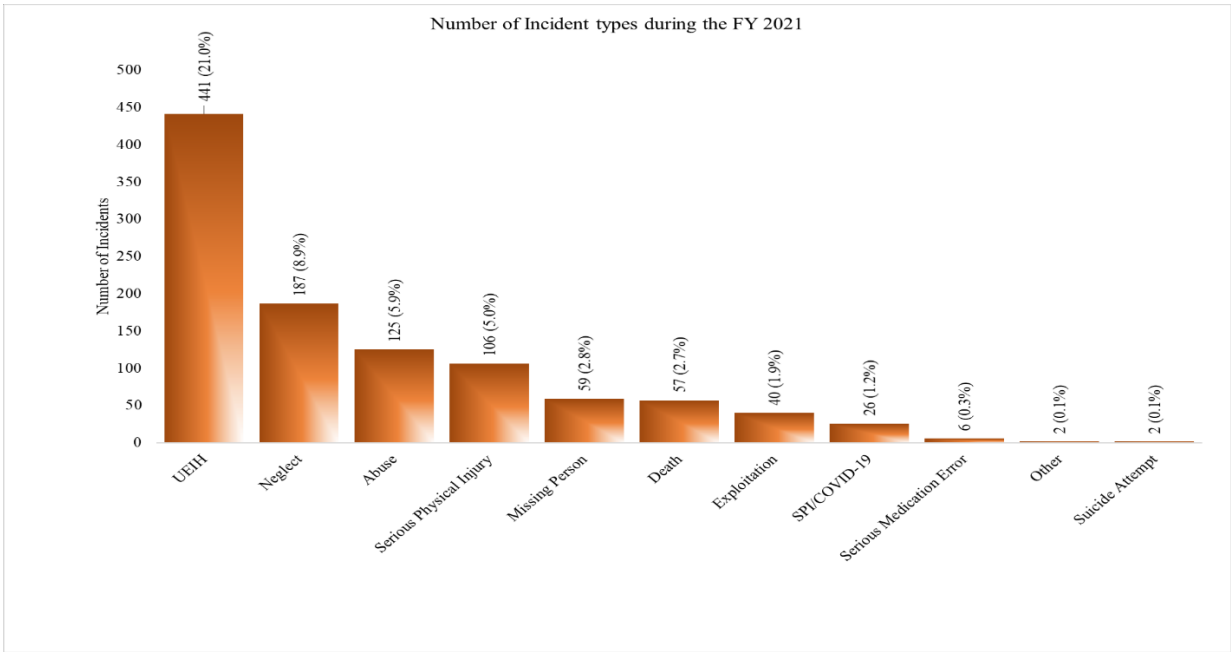


Figure 3. The number of incident types

Figure 3 illustrates that UEIH comprises the maximum number of incidents in 2021. It is 42% of the total and 12% more than the next most frequent incident, which is Neglect.

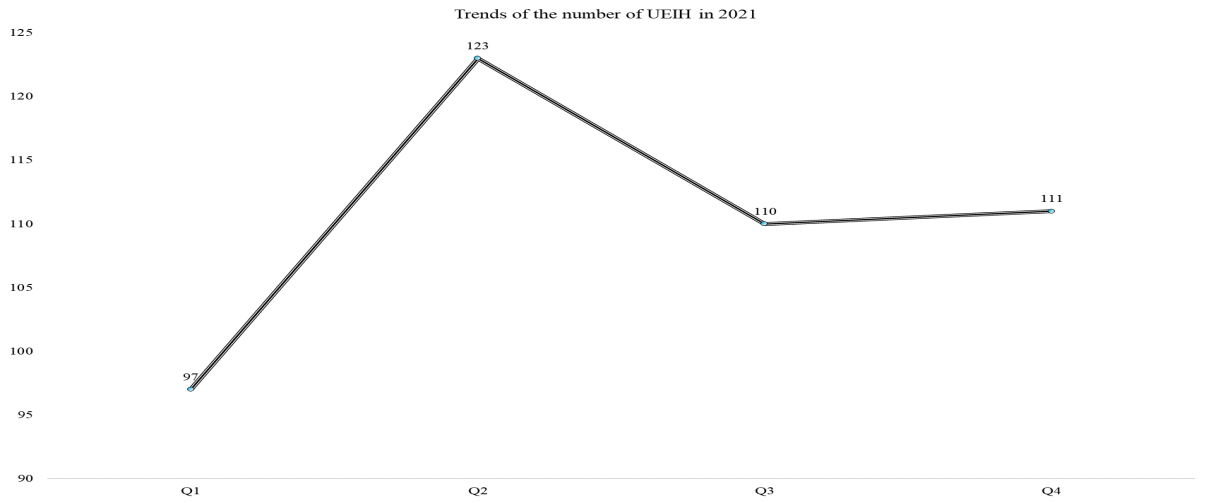
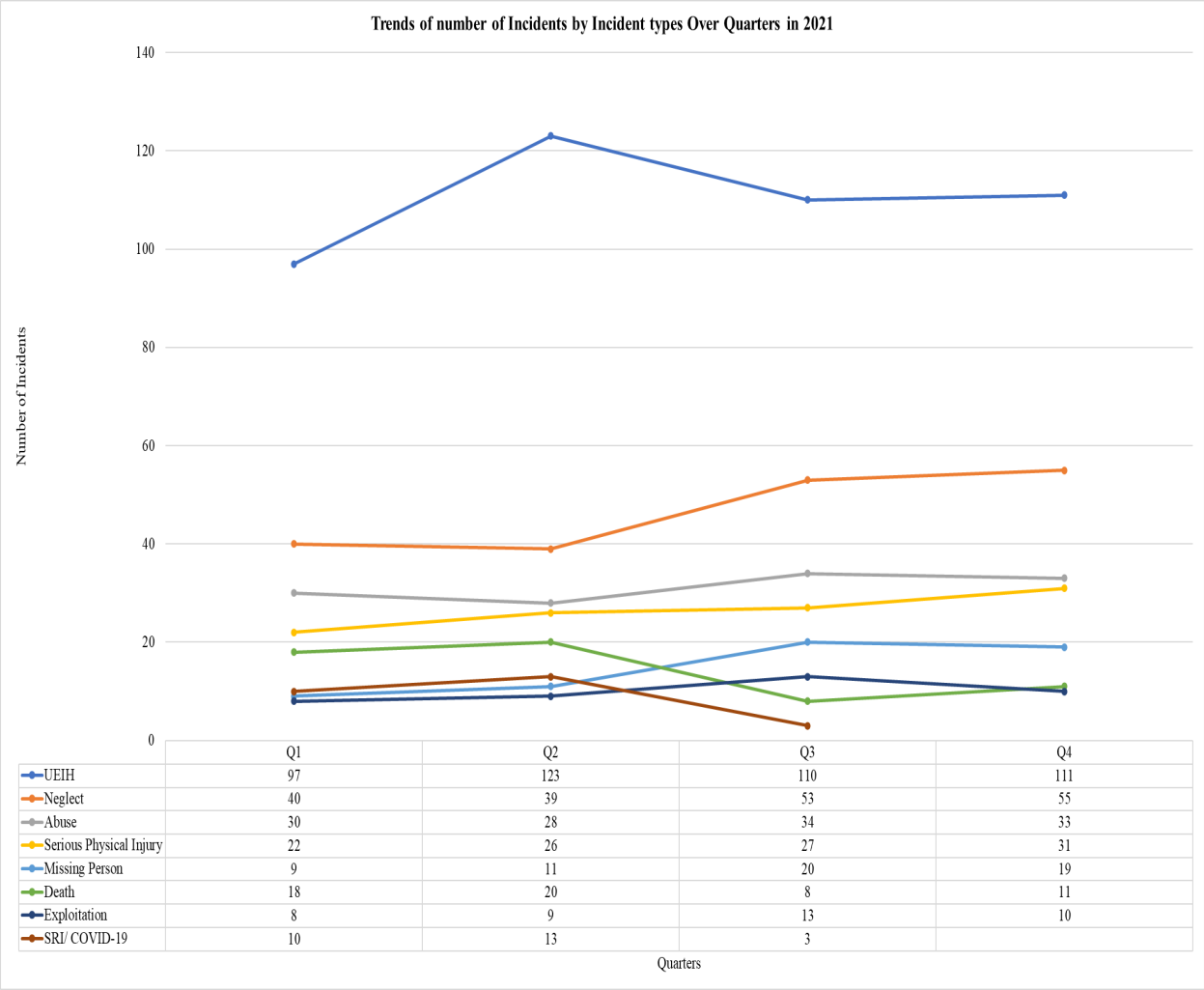


Figure 4. The trend of the number of UEIH incidents in 2021 by Quarters

Figure 4 illustrates that the trend of UEIH incidents is dissimilar from the trend of total incidents, as shown in Figure 1, suggesting that the aggregate of other incidents has more influence than UEIH on the trajectory of incidents in FY 2021.



	Q1	Q2	Q3	Q4
UEIH	97	123	110	111
Neglect	40	39	53	55
Abuse	30	28	34	33
Serious Physical Injury	22	26	27	31
Missing Person	9	11	20	19
Death	18	20	8	11
Exploitation	8	9	13	10
SRI/ COVID-19	10	13	3	

Figure 5. The trend of incidents over time in 2021

Figure 5. shows the trend of all incidents over each quarter in 2021. As was demonstrated in figure four above, there was a significant increase in incidents in the second quarter, led by UEIHs, which then decreased slightly in quarters three and four. COVID-19 incidents also declined from quarter one to quarter three, and then disappeared during the last quarter. The vaccination mandate issued on August 29th might explain this trend.

Service Types and Providers

Table 1. The number of People, Living Arrangement and Residential Providers

Top Five Facilities	Number of Individuals	Percentage breakdown
Supported Living	313	54%
Intermediate Care Facility	96	17%
Natural Home	94	16%
Residential Habilitation	36	6%
Host Home	20	3%
The rest	18	3%
Total	**577**	**100%**
Top Ten Residential Providers		
National Children's Center	36	6%
ST JOHNS COMMUNITY SERVICES	34	6%
METRO HOMES, INC	26	5%
Frontline Community Services	25	4%
Total Care Services Inc.	24	4%
COMMUNITY MULTI-SERVICES	23	4%
Innovative Life Solutions	23	4%
Capital Care Inc	22	4%
RCM of Washington	20	3%
MULTI-THERAPEUTIC SERVICES	19	3%

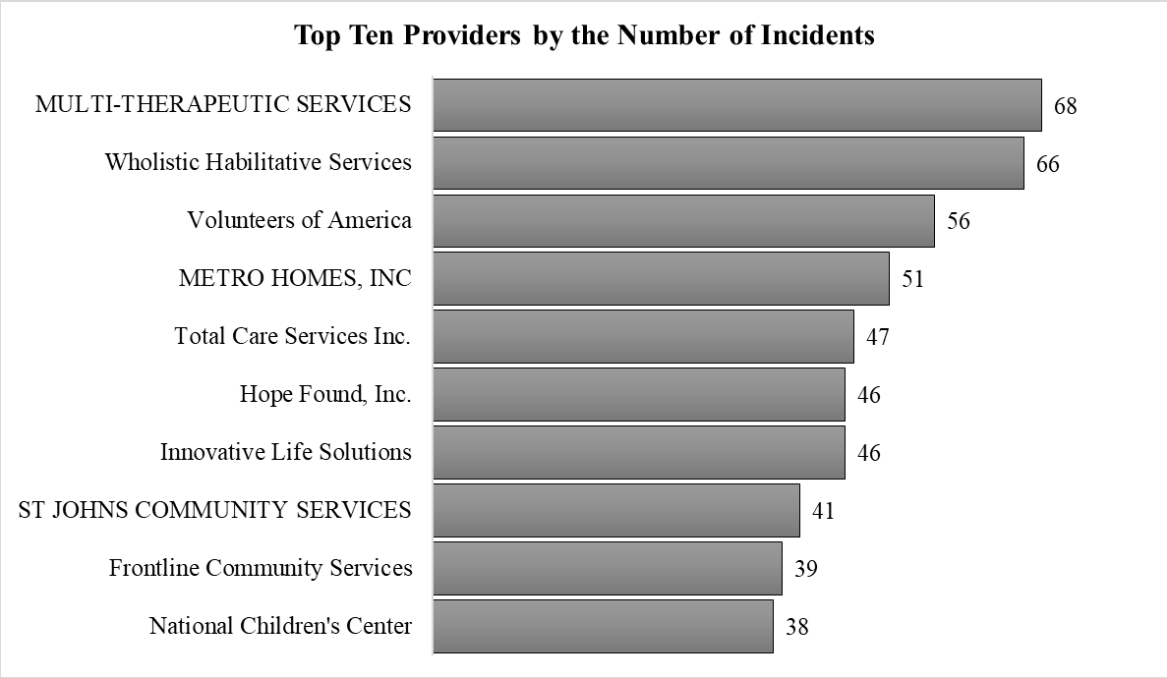


Table 1 displays the top five residential settings where people experiencing incidents live. More than 50 percent live in Supported Living arrangements. The provider who accounted for the largest number of placements is National Children's Center. Even though they support the greatest number of people, they account for the tenth highest number of incidents as shown in Figure 6.

On the other hand, MULTI-THERAPEUTIC SERVICES, supporting the least number of people in the incident dataset 19 (3%), accounted for the largest number of incidents (68 incidents) in FY 2021.

Another factor which needs to be discussed is the proportion of the residential setting reflected in this incident data relative to their proportions of overall settings within the District's IDD system. For instance, Supported Living services are provided to 915 people, or 39% of the approximately 2330 people who are currently receiving services. One third (313) of those 915 people experienced a Serious Reportable Incident which is significant, aside from the fact that they accounted for 54% of all people in the incident dataset for FY 2021. To further highlight this contextual aspect of incident data, let us look at the numbers for people residing in Intermediate Care Facilities. With 260 people living in ICFs/IDD they comprise 11% of all placements. Here again their representation in the SRI dataset is ninety-six people, or 17% of all people who experienced an incident last year. When we look at those ninety-six people within their proportion of overall placements, we see that fully 37% of people who resided in an ICF last year experienced an incident. MTS provides services to forty people in thirteen residential settings of distinct types, including three ICF's in which eight people reside. Frontline on the other hand operates forty-two supporting living arrangements in which fifty-six people live. Clearly MTS oversees larger congregate living arrangements such as ICF, and Residential Habilitation homes, whereas Frontline only uses the apartment model. What this additional level of analysis seems to indicate is that MTS accounted for a disproportional percentage of incidents and Frontline, despite its size reported fewer incidents,

Dispositions of Incidents in Fiscal Year 2021

Status of Incidents

In the reporting period, most incidents have been closed (93%), as shown in Figure 7 below. It should be noted that incidents not yet due accounted for the seven percent of open investigations.

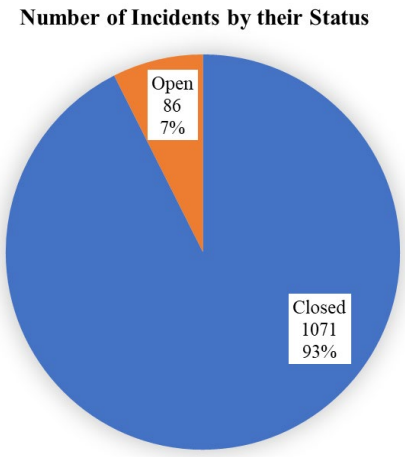


Figure 7. The proportion of Incident status during 2021. Fifty-seven (57) of the open investigations are deaths which are not investigated by DDS. The remaining open investigations were not due for closure as this report was being completed.

Most of the incidents are resolved as No Abuse or Neglect Found. While this disposition is used for more than one incident type it is heavily relied upon for UEIHs, as shown in Figure 9 below.

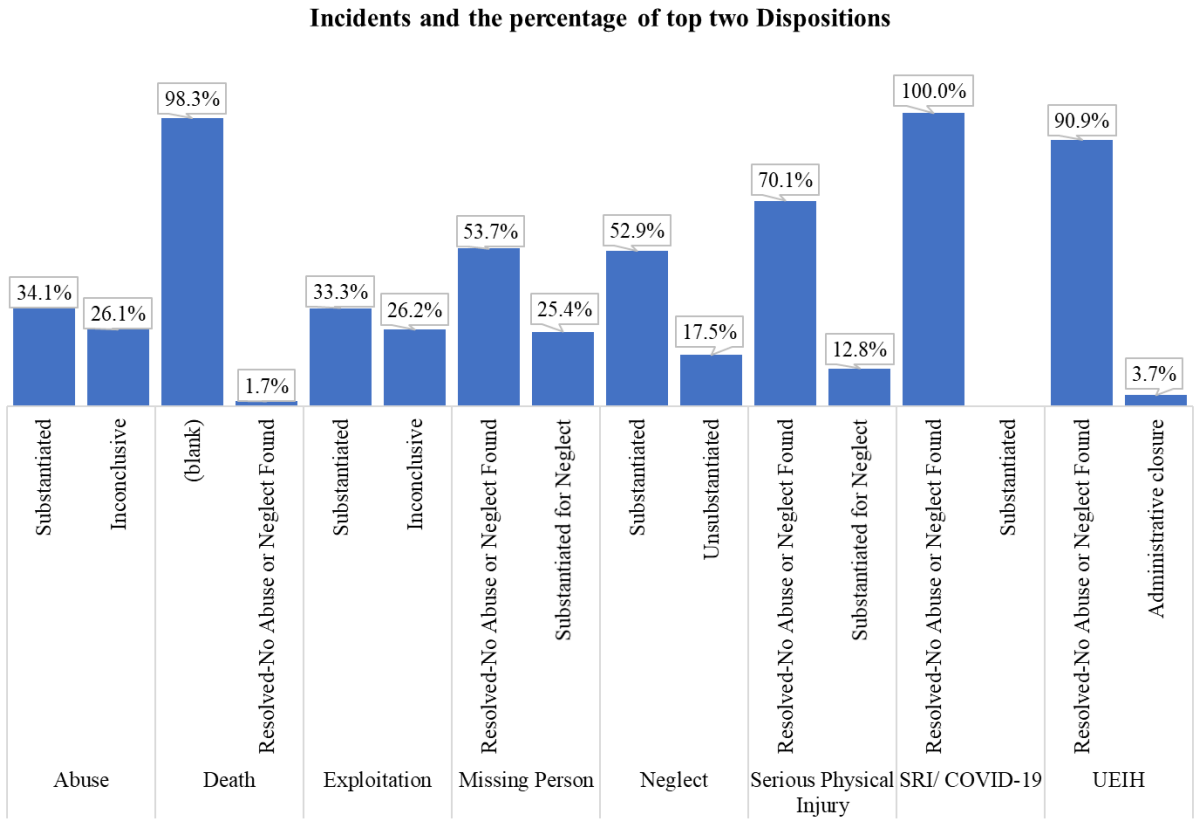


Figure 8. Incident types and the two corresponding dispositions in 2021

Figure 8 demonstrates that more than 90% of UEIH incidents were resolved as no abuse or neglect found. The next highest disposition measure for incidents is Administrative Closers which constitutes only

3.7% of incidents. The second highest incident category is neglect with the top two disposition for those incidents being substantiated (52.9%) or Unsubstantiated (17.5%).

Summary/Recommendations

The data collected, reviewed, and summarized in this report identifies concerns and systemic failures in several broad areas. The primary responsibility for these areas of concern are the residential providers contracted by DDS to support people with disabilities. Through their Service Coordination, Health & Wellness and QI/QA units DDS has responsibility for providing oversight and ongoing monitoring of the services provided in the various settings and shares responsibility for identifying and remedying issues when the delivery of services is not consistent or aligned with individual needs. While disruptions to both provider and government operations during the COVID-19 pandemic has contributed to the problems we identified, this does not reduce the potential for harm to the people being supported because of these failures. We strongly recommend that strategies to address the following areas of concern be developed and implemented to strengthen the basic safety net supports for the people with intellectual and developmental disabilities supported by the DDS/DDA system in the District.

1. **General concerns regarding nursing oversight and documentation**: The Department on Disability Services has implemented several required documents to be completed by nursing staff to direct the person's healthcare. Examples of documents are the Nursing Evaluation, The Healthcare Passport, the Health Management Care Plan and Physician's Orders. These documents are fluid and expected to change as the person's healthcare or condition changes. Hospitalizations, medication changes and new diagnosis and interventions must be added in real time to ensure supports are in line with individual support needs. These documents guide training to Direct Support Staff and nurses as well as assisting hospital staff and other medical professionals. The above-mentioned documents are managed by nursing staff, a Nursing Director and in an ICF, a QIDP. Despite this oversight, our data suggests that this area demonstrates a massive systemic failure. Overall, only 15% of the people monitored had a HMCP, HP and PO that even matched each other. We found these documents are not up to date and do not match each other. More effective monitoring of these documents by the DDA Service Coordinators and Health and Wellness Unit is needed to ensure provider performance improves in this critical area.

2. **Quality of Nursing Assessments:** Our concentrated monitoring focused on healthcare found everyone had a current Nursing Evaluation, however, only 78% were deemed by Quality Trust Nurses to be accurate and informative. Our assessment is based on the Health and Wellness standards established by DDS and accepted nursing practice. We recommend that DDS/DDA renew their focus on ensuring that all provider staff have adequate training and proficiency with their established standards.

3. **Direct Support Professional's (DSPs) training and comprehension of individual diagnosis and subsequent interventions:** DDS/DDA has training requirements for everyone working with the person. The trainings that are specific to the person (phase II) must be updated annually or more often if there is a change in the person's medical condition (new medication, new diagnosis, new intervention, new hospitalization, etc.) Quality Trust Nurses interviewed Direct Support staff and dedicated medical professionals (1:1 medical). Sixty-three percent of those interviewed could NOT recite the person's major diagnosis. QT nurses do not expect DSPs to know every single diagnosis and medication: but they are expecting DSPs will know those that are deemed major and have subsequent interventions (dysphagia, contractures, BSP and psych meds, positioning, constipation problems, diets and eating protocols etc.) DSPs are responsible to implement. Only 60% could recall all the person's recommended interventions. This data would indicate that

greater focus on the importance of documentation accuracy and training and support for DSPs in the use of information and implementation of health supports is needed.

4. **Quality Management Systems:** DDS Service Coordinators, PCR reviewers and Health and Wellness did not detect the provider failures listed above. Despite a vast array of quality management tools and staff, basic information for people is still found to be inaccurate and goes uncorrected. DDS Service Coordinators complete routine monitoring tools as does Health and Wellness. Providers also have systemic monitoring by DDS, such as the PCR review. In fact, DDS has many tools completed by many people that need coordination and analysis. A team had been assembled to address this and other quality issues at DDS (Culture of Quality). This group has not been active during the pandemic so that no measurable advancements towards combining tools and making them more effective has been achieved. The data in this report suggests an urgent need to review and revise the quality management tools and systems used by DDS/DDA to ensure that critical data for people is regularly reviewed in a consistent and accurate manner and results in corrective action to improve the areas of deficiency in services identified. These are basic requirements of any effective quality management system.

5. **Examining the impact of COVID-19**: There is no question that the challenges presented by the Covid-19 pandemic has had a significant impact on the people with intellectual and developmental disabilities in the DDS/DDA system. The preparedness and response to the pandemic varied among the provider community. Some of the data in this report indicates that there is an erosion in the quality and consistency of health care support at the very time of a health-related crisis within the larger community. Providers also experienced staffing shortages that resulted at times in the lack of competent, trained staff available to provide vitally needed close contact personal services and supports. This coupled with the troubling increase in deaths over the past two years warrants further investigation and study. Additional study of both the long-term health impact of COVID-19 for the over 400 people who have contracted it and detailed analysis of the individual and collective data related to the deaths over the past two years would provide valuable insight for understanding the effectiveness of the pandemic response and what changes in practice are needed to address similar challenges in the future.

6. **Changes to services and supports for the future:** Our analysis of the change in the demographics of people seeking support from DDS/DDA indicates that there is an increasing number of young people and a decreasing number of people who are older being supported by DDA. The needs of the younger people now entering the system are markedly different from the people who were supported by the system after the closure of Forest Haven in 1992 and those who entered services over the next two decades. These young people have never experienced institutionalization and have the expectation of greater control within their lives even though they require some assistance.

   In several significant ways the provider-based community living model that dominates services in DC is not in line with the person-directed services envisioned by the New Settings Rules issued by CMS. While DDS/DDA has made significant effort to shift thinking to a more person driven model through training and oversight, the changes in actual practice have been minimal. With the possible changes to eligibility in the proposed bill being considered by City Council and the current staffing challenges, there is increased urgency to provide service options for self-direction in addition to the current one size fits all model for those people for whom such a model makes sense. We know people currently in the system would prefer this model of support. This will allow people with disabilities to obtain the supports they need and experience greater autonomy in their lives. It also makes good fiscal sense as it can increase individualization of service authorizations ensuring people are not over or under supported within a given service model. As pointed out in our introduction, making this shift is an urgent and important strategic issue which should be

embraced and addressed by city leadership in collaboration with providers, advocates, and families.

APPENDIX 1: DATA FROM CONCENTRATED MONITORING

Methodology: Quality Trust nurses reviewed documentation for each person including the HMCP, HP, PO, Nursing Evaluations, Nursing Notes, labs, annual physicals, specialty consults and any related assessments. Interviews were completed with Nurses and Direct Support Staff.

Data collected: 42 people were monitored through this process.

Question	SJCS	Metro	CMS	ILS	Median
Number of people monitored.	20	8	7	7	
People monitored who had an ER visit over the last year.	11/20 (57%)	5/8 (62.5%)	6/7 (86%)	2/7 29%	57%
People monitored who had a UEIH over the last year.	13/20 64%	6/8 (75%)	1/7 14%	0	63%
Current Health Passport.	16/20 (79%)	6/8 (75%)	7/7 (100%)	7/7 (100%)	91%
Current Physician's Order.	20/20 (100%)	6/8 (75%)	7/7 (100%)	7/7 (100%)	85%
Current HMCP.	13/20 (64%)	5/8 (62.5%)	7/7 (100%)	7/7 (100%)	85%
Current Nursing Evaluation.	20/20 (100%)	8/8 (100%)	7/7 (100%)	7/7 (100%)	100%
Current physical.	20/20 (100%)	7/8 (87.5%)	7/7(100%)	7/7 (100%)	98%
HMCP, HP and PO order that matched.	1/20 (7%)	2/8 (25%)	2/7 (29%)	1/7 (14%)	15%
HMCP that included all the person's diagnosis and interventions.	9/20 (43%)	3/8 (37.5%)	4/7 (57%)	3/7 (43%)	36%
Nursing evaluation that accurately captured the person's health.	13/20 (64%)	7/8 (87.5%)	7/7 (100%)	6/7 (86%)	78%
Accurate Health Passport.	7/20 (36%)	1/8 (12.5%)	4/7 (57%)	2/7 (29%)	27%
Physician's Order that was accurate and included all diagnosis and interventions.	6/20 (31%)	3/8 (37.5%)	1/7 (14%)	1/7 (14%)	19%
Specialty appointments	14/20 (70%)	5/8 (62.5%)	2/7 (29%)	5/7 (71%)	47%

completed in a timely manner.					
Medical recommendations followed up on in a timely manner.	10/20 (50%)	6/8 (75%)	0%	3/7 (43%)	34%
Nursing notes were up to date.	16/20 (79%)	8/8 (100%)	7/7 (100%)	7/7 (100%)	76%
Nursing notes that reflected the person's daily health without repetitive wording from day to day.	11/20 (57%)	8/8 (100%)	4/7 (57%)	6/7 (86%)	60%
Needed to see specialty physicians that was not recommended.	8/20 (38%)	1/8 (14%)	2/7 (29%)	1/7 (14%)	39%
Had a medical 1:1.	0%	5/8 (62.5%)	4/7 (57%)	3/7 (43%)	43%
Had staff support.	100%	6/8 (75%)	6/7 (86%)	4/7 (57%)	84%
Staff that could not recite the person's diagnosis.	13/20 (64%)	6/8 (75%)	3/7 (50%)	2/7 (29%)	63%
Could not recite the person's recommended interventions.	11/20 (57%)	6/8 (75%)	3/7 (50%)	2/7 (29%)	61%
Nurses were knowledgeable about the person they supported.	17/20 (86%)	7/8 (82.5%)	6/7 (86%)	7/7 (100%)	91%

Green indicates all providers at 75% or better
Blue indicates all providers monitored were under 60% for that question.
Yellow indicates below 70%

Average performance on 18 questions:

- My Own Place: 12/18 (67%) were not met.
- St. John's Community Services: 11/18 (61%) were not met.
- Community Multi-Services: 10/18 (56%) were not met.
- Innovative Life Solutions: 8/18 (44%) were not met.
- Metro Homes: 7/18 (39%) were not met.

APPENDIX 2: DETAILED REVIEW OF TWO DEATHS BY A CONSULTANT NURSE

Person #1

Ms. K

Mortality Investigation Case #20-0740

Location of death: Her home

Ms. K was able to communicate using vocalizations, gestures and by responding to simple questions by shaking or nodding her head.

Concerns noted in the Columbus Investigation:

1. Complexity of Medical Diagnoses (56 diagnoses entered on the Medical Diagnoses list). History of Aspiration Pneumonia 2013, History of Acute Respiratory Failure 2013 & 2015. PEG Tube placement 2012. Congestive Heart Failure 2019 and Hypercholesterolemia. Diabetes Mellitus Type 2 (January 20, 2020). There was no prescribed treatment or evidence of how glucose readings > 300 were evaluated related to Ms. K's overall health care condition. Topamax was prescribed for ICD but there was no documentation that the medication was prescribed for Seizures.
2. Pulmonologist notes, Ms. K remains at risk for Pneumonia, continue with head elevation after Enteral nutrition, Asthma was controlled in 2019 until exacerbation January 2020.
3. DDS Nurse Consultant's note on 2/22/19 indicated Ms. K was "sticking fingers in her mouth" thought to provoke gag/emesis. Labeled as a behavior. Persons with Gastritis or pain with GERD noted anecdotally to put fingers in the mouth for oral stimulation and assist with GI discomfort. PEG tube dislodged 5/19/19 related to not identified.
4. Proctitis diagnosed during hospitalization 1/17/20. Narrative about diagnosis of Proctitis; Was Ms. K participating in anal sexual relationship, informed, or known?
5. Evaluated by Gastroenterologist 2/24/20 with new PEG tube on 2/26/20. Hospitalized for vomiting 4/3/20 with no clear etiology with possible mild Pancreatitis diagnosis. Topiramate considered to be a source of vomiting. Questionable two episodes of vomiting on the evening of 4/13/20. Was Topiramate prescribed for ICD and for seizure maintenance? According to Neurologist note on 11/8/2019, her neurology plan of care to be continued. Note by HCMP indicated Ms. K had specific concerns of encephalopathy, seizure disorder, cerebral palsy, gait disorder, AMS and syncope. Unsure if these concerns noted by the HCMP were increased or changed Ms. K's health risks or conditions.
6. Evaluated by Endocrinologist 7/19/19 for abnormal thyroid function and thyroid sonogram. Follow Up 8/30/19 revealed Thyroid function test low but no changes in treatment indicated.
7. PCP Visit 1/15/20 indicated that she was doing well and blood sugar of 300 plus thought to be stress Hyperglycemia. There was no identified treatment for the blood sugar of 300 plus. If the Stress Hyperglycemia were thought to be the factor for the high glucose reading, additional monitoring and treatment would be expected. An indication of Stress Hyperglycemia is a marker for severity of endothelial or vascular dysfunction that could alter white blood cell functions and increase risks for fatality. -1/17/20, HCMP note indicated Ms. K specific concerns and interventions of hypothyroid and Mellitus type 2 were detailed and appropriate. Psychiatric/Behavioral list IED, OCD, AMS, Insomnia and history of self-injury behaviors. The AIMS revealed score of 1 for minimal involuntary movement with moderate anxiety, mild aggressive behavior, mild repetitive and mild self-injury.
8. BSP on 1/25/19 and 3/16/20 stated Ms. K was experiencing "intense flailing of arms that included hitting self, hitting others, removing blouse, spitting, screaming, biting self and others, jumping up

and down lasting longer than one minute". The QIDP and HCMP indicated agitation was stable and interventions were appropriate for outlined behaviors. Admitted and Treated for Proctitis (fever and rectal swelling) on 1/4/20 at Howard University hospital. What were symptoms of Proctitis leading staff to summon medical attention? For the Pneumonia, what signs or symptoms?

9. Columbus investigation stated no significant or unusual medical events recorded from 1/16/20 – 3/31/20. PCP visit 4/1/20 increased nausea and vomiting post enteral nutrition. Recurrent vomiting on 4/3/20 at Sibley Hospital with a blood sugar of 300 plus with high potassium and sodium levels. Possible mild pancreatitis where Topiramate was thought to be contributing to elevated levels of lipase. Topiramate was discontinued at time of discharge from hospital, but medication was continued without interruption at her home. COVID testing not done as she had "no fever or other symptomology". At that time, nausea and vomiting were not symptoms associated without fever. More information is known as of this date March 2021 where nausea and vomiting would be investigated as possible precursors to COVID. Discharged to home 4/8/21 and evaluated by PCP on 4/10/20. Vomited 4/11/20 during enteral nutrition, twice on 4/13/20 and no indication enteral nutrition was not given as prescribed by physician's order. Unsure when and what circumstances a Nurse was informed of these vomiting episodes.
10. Ms. K. experienced "breathing heavy and hard breathing" at 5:00 am. No note to indicate an RN was notified at that time due to a change in Ms. K's condition. Support staff called on Call RN who instructed support staff "to keep a close eye on her". To keep a close eye on Ms. K does not provide specific instructions on what to look for, what to do, when to call back the On Call RN and when the situations warranted calling 911 EMS, as Ms. K was experiencing heavy and hard breathing. Another staff reported at 8:00 am that Ms. K was "OK". What does OK mean? Was she experiencing heavy and hard breathing but able to gesture and vocalize? Was she experiencing other signs or respiratory distress, or signs of her usual breathing pattern related to Asthma?
11. On 4/15/20, Ms. K experienced a bowel movement, became weak, could not stand and breathing hard indicating problems with the automatic nervous system. The support staff called the RN who stated that she would come to the home and for staff to put Ms. K on the "breathing machine". What type of breathing machine was ordered and used? As these symptoms evolved to an emergency medical event, at what point could the home staff call 911 EMS? Do they need an order from medical personnel to call 911 EMS? At 12:30, one hour after acute respiratory distress had been evolving, Ms. K's blood pressure was low, and she was pulseless. RN told staff that she would call 911 EMS. An LPN arrived at the home at 12:30 then instructed staff to implement CPR. The Home staff to the Nurse staff communication, failed to initiate CPR and call 911 EMS at the initial onset of respiratory and cardiac distress. DCFEMS reported copious amount of vomitus noted on the floor beside Ms. K. upon arrival to the home. Did home staff have access to Yaeger suction machine? Did staff use Yeager suction if they observed vomitus or excessive secretions in the mouth?
12. The suggestion for staff to put nitrile gloves on Ms. K to defer hand-mouthing behavior is a cardinal mistake. Persons with diagnoses of "hand mouthing" self-injury behavior of biting self and others, repetitive behaviors, gastritis, and dysphagia make the person the highest risk for fatality due to risk of choking on gloves or any other object placed in the mouth. The OCME stated that the office of Chief Medical Examiner looked for evidence of trauma or unnatural causes of death to pursue a full autopsy. It would seem reasonable that additional inquiries would be warranted to determine the cause of death due to the timing of when enteral nutrition was provided, the amount and incidences of vomiting prior to the date of her death. Also, the history of Asthma, Aspiration Pneumonia, unexplained incidences of glucose levels over 300, and Congestive Heart Disease appear to be contributing factors that would elicit a more detailed review of Ms. K's death.

-A comment, there was "no clear evidence that her death was preventable". The specific cause of Ms. K's death may not be directly related to certain factors. However, the history of respiratory difficulties including Aspiration and Bronchial Pneumonias, Asthma, Seizure Disorder, Congestive

Heart failure, two recent hospitalizations at two different hospital systems, and incidences of hyperglycemia put her at highest risks for adverse health conditions and fatality.

13. Page 16: Recommendations for the provider: Recommend staff to be adequately trained to perform CPR, BLS and staff to recognize a change in the person's condition. The recommendation of incomplete health care diagnoses, would diagnoses added to the Health Passport make a difference to front line staff caring for Ms. K? Staff should be given the detailed instructions and parameters on what to do for the person during the actual time of acute and medical emergencies. It appears that there is already a mechanism that provides for direct staff to nurse contact and communication. General Health and Wellness instructions may be generic and not as obvious as to what Ms. K needed. It would be important for staff to understand and perform basic tasks of removing excess secretions from the mouth with oral mouth suction device and the importance of maintaining proper positioning after enteral nutrition.
14. Ms. K's death was listed as natural. The obvious signs and symptoms of respiratory difficulty and visible amounts of copious vomitus secretions make it difficult to understand how the manner of death was classified as natural.

General Comments after data review for Ms. K:

After reading the Columbus Death Investigation for Ms. K., we are left with more questions than answers. There are problems regarding her care in the years leading up to her death that rise from the available documentation we reviewed. In rereading MCIS documentation covering the two years prior to her death, several problems were noted. Documentation studied included Serious Reportable Incidents and Reportable Incidents, Issues, Service Coordination Monitoring Tools, Health and Wellness Monitoring Tools and Service Coordination Progress Notes.

Previous Incidents:

- 1/30/19 ER visit -PEG tube leaking. The LPN notices the leak while completing the morning feeding. At that time, the DSP reports that it had been leaking during the night as well. It is concerning that the DSP noticed the G-tube leaking during the overnight shift yet did nothing until the nurse showed up for routine morning PEG tube feeding.
- 2/12/19 ER visit- PEG tube leaking. Upon admission she was diagnosed with lethargy, hypotension and pneumonia, ulcer, and gastritis.
- 5/29/20 ER visit- PEG tube found completely out and between her legs.
- 1/4/20 UEIH-Ms. K went to the emergency room on 1/4/20 when staff noticed a red bulge protruding from her anus. DDS NP notes indicate that she had a fever of 101 and was tachycardic. She was treated for proctitis, pneumonia found on a CT scan, sepsis 2nd digit right hand. She was given broad spectrum antibiotics "to cover all her infections". While hospitalized it was recommended that she receive a colonoscopy, but the hospital staff could not get consent. The limited guardian was initially not responsive, but eventually the colonoscopy was completed. Ms. K. was discharged on 1/10/21 without a discharge meeting. The provider's Director of Nursing reportedly did not feel it was necessary.
- 4/3/20 UEIH- On 4/3/21 Ms. K. went to Sibley Hospital for vomiting after her feedings. A CT scan showed pneumatosis in the colon. Pneumatosis can be a benign disease that requires no treatment. In other cases, it is secondary to other gastrointestinal and non-gastrointestinal diseases. It is unclear if this was primary or secondary as notes to not indicate this level of detail. She was discharged on 4/7/21. A teleconference discharge meeting occurred with the provider nurse, the DDS SC and DDS nurse were present.
- Death 4/15/20 The incident as written is below. There is no mention of vomiting in this report, yet the Columbus Investigation notes she "was covered with copious amounts of vomitus." Why was this left off the report? What else might not have been included on the report?

Ms. K. was in her home, preparing for her afternoon feeding. M (Companion staff) was in the bathroom with Ms. K, changing her adult undergarment, when she realized Ms. K was becoming very weak and her breathing was not normal. M called the RN, J to relay the concern about the breathing. J instructed staff to administer her breathing treatment. At the same time J immediately contacted 911. LPN B arrived at the home around 12:30p, to provide the afternoon feeding. When she arrived, she noticed that Ms. K was in the Living Room and not really tolerating the breathing treatment. Berlinda reported that she checked her pulse and did not feel a pulse, she instructed the staff to begin CPR. As CPR was being performed, the Paramedics arrived and they took over performing CPR, after about 25 minutes and still no pulse, the paramedics declared Ms. K deceased.

Concerns after reviewing MCIS:

The provider has a Disposition Letter dated January 1. It concluded that they were not neglectful in the care Ms. K received entering the January 4, 2020, unplanned hospitalization. They listed her discharge diagnosis only as proctitis of the lining of the rectum. However, she was also diagnosed with pneumonia, fever, and sepsis of right 2nd digit. Considering her multiple diagnoses, this conclusion may not be accurate. If she had a fever of 101 degrees, pneumonia, and sepsis in an infected finger, one could postulate that she was significantly more ill than reported by the provider.

DDS Service Coordination Notes: 12/20/18 note: The DDS SC notes that the provider had purchased $10,000 in life insurance policies for some people in its care from their BSA account. The provider was to send the cost and plan to the SC for review. Why would Ms. K. need $10,000 in life insurance?

There was no note for Ms. K.'s ER visit on 1/30/19

- 2/14/19 note: Ms. K went to the ER for lethargy, hypotension, and weakness. There is no mention of the PEG tube being dislodged. She was diagnosed with pneumonia, gastritis, and an ulcer. She required a transfusion of packed red blood cells. It was recommended she follow up with the Gastroenterologist and have a colonoscopy.
- 2/16/19-The SC notes he went to the hospital to visit Ms. K and learned she had been discharged. Neither the hospital nor SJCS let him know about the discharge meeting.

Health and Wellness completed a Monitoring Tool on June 26, 2019. It was the last tool completed by H&W. The assessment listed the following issues:

- Ms. K. had not received the pneumonia vaccine, or the second Varicella shot.
- The Health Passport did not include Hepatitis B or C, Chronic Systolic congestive heart failure, thyroid nodule, or Parkinson's Disease.
- The HCMP does not have measurable goals.
- There was no current psychiatric evaluation despite Ms. K being on 4 psychotropic medications.

-8/23/18 PCP recommendations for a urinalysis and UDRL (syphilis test) and a vitamin D test could not be located.

-2/1/19 the Endocrinologist recommended a thyroid sonogram, TSH, T4 and TPO antibody level checked. As of 6/29/19 it was not completed.

-No current Nutrition assessment.

A Service Coordination Monitoring Tool was completed the day after Health and Wellness completed their tool. This tool is in complete contrast to the Health and Wellness tool. There were no issues found and the Service Coordinator answered the following questions in contrast to H&W.

1. Is there evidence that recommendations made by the physician are implemented?

-answered yes, (H&W could not locate the recommended urinalysis, UDRL or vitamin D levels the previous day)

2. Did medical specialist's recommendations get implemented?

-answered yes (H&W could not locate the thyroid sonogram, TSH, TS or TPO antibody tests the previous day)

3. Is there a current nutrition assessment?

- answered yes (H&W reported there was no current Nutrition assessment the previous day).

4. Are recommendations from the nutrition assessment being implemented?

-answered yes (but there is no current assessment to implement as per H&W.)

5. Were diagnostic consults ordered-answered yes. Were those orders followed?

-answered yes (H&W reported that thyroid diagnostic tests were not completed).

6. Is adaptive equipment working?

-answered yes despite the comments section of the tool reporting that the wheelchair is broken, and a team meeting is needed to discuss it.

DDS/DDA Issues Review:

1. There were several issues generated after the Health and Wellness tool was completed, as well as for previous issues.

2. Digoxin levels were not completed. Identified on 6/26/19. Closed 7/20/19. The last recorded labs were dated 2/1/19. These levels should be checked regularly and levels that are too high can cause nausea/vomiting, stomach pains, change in heartbeat.

3. The Sibley D/C reported that the medication Topiramate may be causing the vomiting and nausea. The provider nursing staff had no documentation that this was discussed with the Primary Care Physician, so the medication was never stopped, and Ms. K. had subsequent bouts of vomiting after this recommendation. The issue was resolved the day she died.

4. Broken wheelchair. Identified on 2/6/20, yet the Service Coordination Tool identified the problem on 6/27/19. Another issue (200300-0660-001 identified the wheelchair as broken 1/4/20. The chair was not fixed until 2/12/20. A delay of a year from the first report in a Service Coordination Tool until the wheelchair was working again.

BSP concerns:
1. BSP pre review: There was no evidence of staff training, and the medications did not match across various documents.

2. Ms. K. had a BSP revision on 3/16/20. Her target behavior is listed as agitation. The writer of the BSP (Dr. Byrd) reports that the function of the behavior is avoidance, attention, and to relay the feeling of pain. There are over 20 pro-active strategies to address the target behaviors. There is one strategy that may relate to pain; that was for her to have regular bowel movements. There was no other discussion of how pain should be addressed, what to look for, who to contact, etc. There is no discussion in the staff response section to address possible pain.

3. It should be noted that Ms. K. took four psychotropic medications and had a 1:1 staff by default at her home and 1:1 staff in day habilitation as well due to behavior.

4. As the QIDP for Ms. K. from 2000-2003 one writer of this report knew Ms. K. It was well understood at the time that Ms. K.'s behavior was a direct result of physical discomfort and pain. She had behavioral challenges every month during her menses and had gastrointestinal pains. It was known that she suffered

from GERD, and it was discussed that this caused much discomfort to her, and during those times Ms. K. usually didn't want to eat. She had to be prompted throughout her meal to continue to eat her meal. It was believed that eating caused her subsequent discomfort. It was thought at the time that the mouthing of her fingers was not to make herself vomit (which she rarely did) but rather to show discomfort due to GERD. It is disappointing that her BSP does not appropriately address the seriousness of her various GI diagnosis and subsequent behaviors.

Person # 2

This review was shorter in nature due to Mr. E having Covid at the time of death, therefore the review into how he may have died was not necessary. We did however find some concerning issues with the care provided by his provider that are noted.

Mr. E

Mortality Investigation Case #20-0771 (Covid)

Location of Death: Washington Hospital Center

Mr. E was a 60-year-old African American man who lived in an ICF/DD home starting in 1982 and his final residential move to another home withing the same company in 2015. His brother was prominent in his life as a frequent visitor and his legal Guardian. According to documentation, Mr. E, was an active volunteer (not paid) at The Soldiers' Home twice a week, one day at the Central Mission and two other days at community activities.

Mr. E's Intellectual/Developmental Disability Diagnosis is Severe Cognitive Intellectual Disability and Severe Adaptive Intellectual Disability. His Medical Diagnoses include more than thirty medical diagnoses on his Health Passport and more than ten diagnoses that were not on his last March 26, 2020, Health Passport.

Concerns noted prior to death:

1. A consult for Endocrinology was not obtained despite numerus diagnoses such as Diabetes Mellitus, Elevated Prolactin Levels, Polydipsia, Hypogonadism, Gynecomastia, and Thyroid Cyst on his medical problem list which requires endocrine specialist continuing consultations. It is important to understand the importance of seeking specialty consultation to provide baseline information about a symptom, illness, or disease to track, monitor and treat for effective outcomes.
2. Orders for A1C serum levels were obtained for glucose checking which are documented as within the normal range. Polydipsia has two arms, psychogenic and discogenic. Psychogenic is related to psychiatric illnesses of intellectual disabilities and schizophrenia and discogenic is excessive drinking of copious amounts of fluid where individuals have the impression that consumption of water relates to good health. For example, an endocrinologist would provide parameters of care for differentiating the symptoms of Diabetes Mellitus and Diabetes (Pituitary) Insipidus (Polydipsia). The objective for staff to know, understand and report the causation of thirst or excessive drinking fluids, urinating frequently or urinating repeatedly.
3. It is likely that the elevated Prolactin levels are related to the prescription of Prozac for obsessive compulsive disorder or Risperdal for Intermittent Explosive Disorder. It should not be automatically assumed that conditions such as Hyperprolactinemia are related to undesirable side effects of medications. Each adverse sign or symptoms of a medical condition or illness requires assessment and evaluation. The Psychiatrist documented "no" in the Psyche Review that increased Prolactin levels were related to prescribed medications. It is documented in Mr. E's health care record that his prolactin levels continued to rise from 43.6 in April 2019 to 47.7 in January 2020. The continued rise in the prolactin levels warrant further investigation especially as he had a Right Thyroid nodule, obesity, hypogonadism, and gynecomastia. All these diagnoses

with altered Mental Status could potentially be related to more serious conditions such as Thyroid disorder, Pituitary tumors or Pituitary adenomas unless investigated. An Endocrinologist should have been intrinsically involved to manage systems of increased Prolactin levels along with the other Endocrine system concerns.

4. The Columbus report indicated the HCMP did not address medical issues in the monthly March 31, 2020, reports for Constipation, Hemorrhoids, Blepharitis, Endocrinological concerns, Seizure disorder, Elevated PSA levels, Diagnoses of BPH, Atypical Psychosis, Intermittent Explosive Disorder and Self Injury.
5. Health Wellness vaccine, Shingrix was not given, unsure if all series of Hepatitis A & B, and Pneumovax PCV (23) were administered. Influenza Vaccine for Year 2019 was not administered as ordered.
6. A diagnosis of Obstructive Sleep Apnea is recorded in Mr. E's official records along with an increased risk of aspiration due to this disorder. The Columbus Mortality review reveals Mr. E. refuses to wear the CPAP at night. There was a case conference held on 3-01-19 that discussed the problem of Mr. E. sleeping while at his day program. The problems with Mr. E. not being able to tolerate the CPAP treatments did not enter this discussion.
7. On 8-8-19, the Service Coordinator completed a monitoring visit. She stated that Mr. E. chews on his CPAP and it was discussed with the QIDP and the RN that they would attempt to identify an alternative CPAP treatment. This issue was never mentioned again by the Service Coordinator nor evidence of alternative measures provided to assist Mr. Brown wear the CPAP machine exists. There is no mention in Mr. Es 11-22-19's BSP that he chews on his CPAP machine as mentioned in his residential notes.
8. It is also important to note that it was documented in the psychological reassessment on 11-18-19 that the lack of sleep made his once lessening behaviors, much worse. Documentation notes indicate Insomnia was a current diagnosis and Benadryl was administered at night for sleeplessness. However, there is no report that Benadryl was or was not effective. There is no documentation to indicate whether the possibility of Benadryl's paradoxical effect of Central Nervous System stimulation (inability to Sleep, Irritability) contributed to sleeplessness at night. There is no documentation evidence that alternative measures were provided for Mr. E's inability to tolerate the application of the CPAP machine. Trials of dental appliances such as dental guards, adjustments of straps on the CPAP machine and side positionings for sleep are simple measures that should be tried at a minimum when persons have difficulty wearing CPAP machines.
9. Mr. E's gastrointestinal history indicates a history of Obesity, Dilated Esophagus, Rumination, Internal and External Hemorrhoids, and Gastritis. LA grade A Reflux/Esophagitis was diagnosed via endoscopy on 4-18-16 and follow up with Gastroenterology (GI) was recommended. A GI follow up was completed on 9-1-16, the physician repeated LA grade A Reflux/Esophagitis as the diagnosis and to "continue current regimen". No other documentation was added at this visit or any of the reoccurring GI consultation visits. A Speech assessment noted on 12-08-16 that a Modified Barium Swallow had been requested. However, there is no record that this diagnostic evaluation was completed. It is most likely that daily Rumination over a long period of time contributed to his diagnosis of LA grade A Reflux/Esophagitis. His plan of care does not indicate any preventative Rumination regimens such as carbohydrate loading (offering increased amounts of carbohydrate foods multiple times a day). Also, Rumination preventative measures of walking immediately after meals to facilitate gastrointestinal tract motility and digestion of foods and fluids was not a part of his usual health care regimen.
10. Mr. E had a diagnosis of Benign Prostatic Hypertrophy with benign nodules and elevated Prostate Specific Antigen (PSA) levels. He was being followed by a Urologist who reports his PSA levels have been elevated at 4.1 & 6.6 in 2016, 5.1 in 2017, 7.3 in 4/16/18, and 6.7 in 5/24/19. The Urologist's plan of care included a biopsy under anesthesia or a Magnetic Resonance Imaging (MRI) to evaluate the prostate gland due to his history of BPH and elevated PSA levels. PSA

levels greater than 4.0 -10 ng/ml usually require investigation to determine if there is cancer of the prostate gland. Mr. E is 60 years of age and African American which puts him at 2.2 increased risk for malignancy. Medical literature suggests taking more assertive measures when PSA levels are continuously elevated as documented for DB. However, these lab values are in the gray area where the judgment and responsibility of obtaining a biopsy, MRI and/or other form of treatment remain with the Urology Consultant.

11. The Mortality reported indicated the diagnosis of Seizures was deleted from his medical problem list, August 10, 2018. There is no evaluation of break through seizures or documentation when antiepileptic medications were discontinued. There is no evidence if antiepileptic medications were abruptly discontinued or if medications were titrated then discontinued. Mr. E's medical history does not reveal any episodes of Seizures even during the April 2020 hospitalization admission at the end of his life.
12. The Annual Psychiatric Evaluation dated 12/10/2018 for Mr. E states "after the date of this report, please consult current record for changes in psychiatric/behavioral and medical concerns. If there are no significant changes in diagnosis behavior or pharmacologic, then the Psychotropic Medication Reviews should be considered as psychiatric assessment updates and no other psychiatric assessments should be done until after four years". It appears that the Psychiatrist is considering Mr. E's psychological assessment evaluation to be stable and not at risk for life threatening conditions and behaviors. His assessment on 11/22/19 indicate his target behaviors are physical aggression (pulling, grabbing, or hitting others), snatching food and drink, self-stimulation/repetitive behaviors (licking and or kissing furniture, walls windows, sockets shoes and touching objects repeatedly, and self-injury (hitting self or banging head against objects). His monthly Psychiatric Review was completed on February 02, 2020, indicated interventions for his behavior were detailed and appropriate. There is no documentation to evaluate Mr. E's behaviors as stable with the prescribed medication regimen or if his target behaviors increased.
13. Reports and documentation of Mr. E's initial symptoms around 4/8/20 of fever, lethargy, cough, and notification of medical support to assess and evaluate signs and symptoms of illness seemed to be reported timely with appropriate health care practitioner responses. It appears that the primary PCP performed a telehealth medical appointment on 4/10/20, quarantined Mr. E due to fever and lethargy, given Zithromax and Tylenol then admitted to the hospital on 4/12/20 after testing positive for COVID. A QIDP visit to Mr. E's homes on 4/13/20 revealed the CMS home was operating according to The Mayor of the District of Columbia's established COVID policies and procedures. The written summary of the hospital course revealed a MICU admission with varying degrees of improvement then an acute deterioration occurred with death on 4/22/2020. It appears the hospital maintained close contact and communication with the home and Mr. E's legal guardian, his brother. The ending cause of death is acute respiratory distress syndrome, Pneumonia, COVID-19 with Hypertensive Cardiovascular Disease.

APPENDIX 3: SRI Follow Up Monitoring DATA

Type and Number of Serious Reportable Incidents Reviewed

Type of Incident	Number Reviewed
Abuse	27
Neglect	25
SPI	21
UEIH Medical	13
UEIH Psychiatric	5
MP	9
Exploitation	7
Other	2

Service Coordination questions:

- Did the DDS Service Coordinator give an accurate overview of the incident and their response when asked via phone interview?
    - Yes: 93/109 (86%) No:12/109 (11%) N/A 3/109 (3%)
- Was there Evidence that the DDS Service Coordinator acted after the incident?
    - Yes 88/109 (81%) No 27/109 (25%).

Abuse Incidents: 27

Types of Abuse:

Verbal	13/27 (48%)
Physical	9/27 (33%)
Sexual	2/27 (7%)
Other	3/27 (11%)

Alleged Abuser:

Residential Staff	24/27 (89%)
Other (spouse, stranger, family, etc.)	3/27 (11%)

Where the Police called?

Yes	3/27 (11%)
No	18/27 (67%)
N/A	6/27 (22%)

Neglect Incidents: 25

Type of neglect	Number
No 1:1	3/25 (12%)
Not enough staff present	6/25 (24%)
Environment	2/25 (8%)

Medical	6/25 (24%)
Other	8/25 (32%)

- Based on the above number for medical neglect, 1/6 people (4%) went to the hospital due to the neglect.

Who was alleged to be neglectful?

Residential Staff	19/25 (76%)
Other (but not day program staff)	6/25 (24%)

Did the person have multiple neglect incidents?

Yes	6/25 (24%)
No	19/25 (76%)

Exploitation: 7

Who was alleged to have exploited the person?

Residential Staff	4/7 (24%)
Family	1/7 (14%)
unknown	2/7 (29%)

Where the police contacted?

Yes	1/7 (14%)
No	6/7 (87%)

Serious Physical Injury: 21

Did the person have a diagnosis which made them more likely to have a SPI?

Yes	9/21 (43%)
No	12/21 (57%)

Did the person go to the hospital for treatment?

Yes	14/21 (67%)
No	7/21 (33%)

Did the injury happen because of a behavioral incident?

Yes	4/21 (19%)
No	17/21 (81%)

- 4/4 (100%) of people who had an injury due to their behavior had a current BSP.

Were D/C recommendations followed?

Yes	14/18
No	4/18

Did the HMCP, HP and PO match?

Yes	7/18
N0	11/18

Where nursing notes up to date?

Yes	17 17/18
No	2/18

Psychiatric Hospitalizations- 7/18

Did the person go to CPEP?

Yes	5/7 (71%)
N0	1/7 (14%)
N/A	1/7 (14%) out of state

Were the police involved?

Yes	6/7 (86%)
No	1/7 (14%)

Has the person been arrested over the last year?

Yes	4/7 (57%)
No	3/7 (43%)

Did the person have a current BSP?

Yes	7/7 (100%)

Does the person have increased staffing?

Yes	5/7 (71%)
No	2/7 (29%)

Missing Person-9

Does the person have multiple MP incidents?

Yes	6/9 (67%)
No	3/9 (33%)

Does the person have a BSP that addresses missing person incidents?

Yes	6/9 (67%)
No	3/9 (67%)

Interview of staff-110

Were staff knowledgeable about the person?

Yes	90/110 (82%)
No	9/110 (8%)
N/A	11/110 (10%) Staff not available for interview

Did the interview with staff require QT to report a SRI?

Yes	3/110 (3%)
No	107/110 (97%)