

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

Table of Contents

List of Tables iii

List of Figures iv

EXECUTIVE SUMMARY 1

INTRODUCTION 2

METHODOLOGY 8

Data Extraction and Transfer 8

Data Cleaning and Pre-Processing 8

Data Analysis 9

Data Visualization 9

RESULTS AND DISCUSSION 10

Who Made Up the “System?” 10

Demographic Composition of DDA Service Recipients..... 11

Gender 13

Age..... 13

Race..... 14

Residential Settings Type..... 15

Service Providers..... 17

ANALYSIS OF INCIDENT AND INVESTIGATION DATA 19

People with Incidents 19

Number of People and Incidents..... 20

Incident Type Description 22

Trend of UEIH Incidents 24

UEIH by Gender and Time..... 24

UEIH by Person for Evans Class/Non-Class Members 25

Death by Gender, Person over Time..... 26

Dispositions of Incidents Over the Ten Years 27

CONCLUSIONS..... 31

List of Tables

List of Tables iii

List of Figures..... iv

EXECUTIVE SUMMARY 1

INTRODUCTION..... 2

METHODOLOGY 8

Data Extraction and Transfer 8

Data Cleaning and Pre-Processing 8

Data Analysis 9

Data Visualization 9

RESULTS AND DISCUSSION 10

Who Made Up the “System?” 10

Figure 1. Trends of number of people receiving services from DDA..... 11

Table 1. The number of admissions and exits of people receiving service from DDS/DDA 11

Demographic Composition of DDA Service Recipients..... 11

Table 2. Demographic composition of a unique number of all service recipients 12

Gender 13

Figure 2. Gender composition of people receiving service from DDA..... 13

Age..... 13

Figure 3. Proportion of total male and female service recipients by age group since 2011 . 14

Race..... 14

Figure 4. The proportion of people by race and gender of the total service recipients since 2011..... 15

Residential Settings Type..... 15

Figure 5. Visualization of yearly trends of the number of residential placements of service recipients from 2011 to 2020. 17

Table 3. The breakdown of residential placements over the period of the report..... 17

Service Providers..... 17

Table 4. The top ten service providers and their corresponding placements from 2011 to 2020..... 18

ANALYSIS OF INCIDENT AND INVESTIGATION DATA 19

People with Incidents 19

Table 5. The number of people who received services with and without incidents over the years.	19
Number of People and Incidents.....	20
Table 6. The frequency of incidents per person	20
Table 7. Demographic distribution of service recipients who experienced at least one incident.....	21
Incident Type Description	22
Figure 6. Trends of the number of UEIH over 10 years period from 2011 to 2019.??.....	22
Figure 7. The trends of the number of major incidents from 2011 to 2020.....	23
Trend of UEIH Incidents	24
Figure 8. Quarterly trend of UEIH from 2011 to 2020	24
UEIH by Gender and Time.....	24
Figure 9. The percentage of UEIH incidents by gender and over time.	25
UEIH by Person for Evans Class/Non-Class Members	25
Figure 10. The trends of UEIH incidents experienced by Class and Non-Class Members since 2011.	26
Death by Gender, Person over Time.....	26
Figure 11. Trend of the number of deaths for female and male Class and Non-Class members over time.....	27
Dispositions of Incidents Over the Ten Years	27
Figure 12. The number of dispositions taken for each incident over time since 2011	28
Table 8. The distribution of dispositions for all incidents between 2011 and 2020	28
Table 9. Combination of the number of incidents and their corresponding dispositions during the ten-year period since 2011.....	30
CONCLUSIONS	31

List of Figures

List of Tables	iii
List of Figures.....	iv
EXECUTIVE SUMMARY	1
INTRODUCTION.....	2
METHODOLOGY	8

Data Extraction and Transfer	8
Data Cleaning and Pre-Processing	8
Data Analysis	9
Data Visualization	9
RESULTS AND DISCUSSION	10
Who Made Up the “System?”	10
Figure 1. Trend of number of people receiving services from DDA	11
Table 1. The number of admissions and exits of people receiving service from DDS/DDA	11
Demographic Composition of DDA Service Recipients.....	11
Table 2. Demographic composition of unique number of all service recipients	12
Gender	13
Figure 2. Gender composition of people receiving service from DDA.....	13
Age.....	13
Figure 3. Proportion of total male and female service recipients by age group since 2011 .	14
Race.....	14
Figure 4. The proportion of people by race and gender of the total service recipients since 2011.....	15
Residential Settings Type.....	15
Figure 5. Visualization of yearly trends of the number of residential placements of service recipients from 2011 to 2020.	17
Table 3. The breakdown of residential placements over the period of the report.....	17
Service Providers.....	17
Table 4. The top ten service providers and their corresponding placements from 2011 to 2020.....	18
ANALYSIS OF INCIDENT AND INVESTIGATION DATA	19
People with Incidents	19
Table 5. The number of people who received services with and without incidents over the years.	19
Number of People and Incidents.....	20
Table 6. The frequency of incidents per person.....	20
Table 7. Demographic distribution of service recipients who experienced at least one incident.....	21
Incident Type Description	22
Figure 6. Trends of the number of UEIH over 10 years period from 2011 to 2019.??.....	22

Figure 7. The trend of the number of major incidents from 2011 to 2020	23
Trend of UEIH Incidents	24
Figure 8. Quarterly trend of UEIH from 2011 to 2020	24
UEIH by Gender and Time.....	24
Figure 9. The percentage of UEIH incidents by gender and over time.	25
UEIH by Person for Evans Class/Non-Class Members	25
Figure 10. The trend of UEIH incidents experienced by Class and Non-Class members since 2011.	26
Death by Gender, Person over Time.....	26
Figure 11. Trend in the number of deaths for female and male Class and Non-Class members over time.....	27
Dispositions of Incidents Over the Ten Years	27
Figure 12. The number of dispositions taken for each incident over time since 2011	28
Table 8. The distribution of dispositions for the total incidents between 2011 and 2020	28
Table 9. Combination of the number of incidents and their corresponding dispositions during the ten-year period since 2011.....	30
CONCLUSIONS	31

EXECUTIVE SUMMARY

This report of demographic and incident data was made possible by collaboration between Quality Trust for Individuals with Disabilities (Quality Trust) and the Department on Disability Services (DDS) as well as research and analysis by a Georgetown University Pre-Med intern and a PhD data analyst. The report looks deeply into the demographic characteristics of the system of services and supports provided to people who experience intellectual and other developmental disabilities in the District of Columbia, and we also cover the incidents and investigations that occurred between years 2011 and 2020. That decade was marked by several significant developments. Although the *Evans* case was not concluded until January of 2017, initiatives undertaken just prior to and during this decade supplied the improvements necessary to conclude the case. The most significant system improvement made during this time was the implementation of the first substantial HCBS (Home and Community Based Services) Medicaid waiver which took effect in the fall of 2007. By 2010, the migration of local and federal spending into the budget of the Department on Disability Services was well underway. As a result, the migration away from the ICF/IDD program to waiver funded services could be achieved in the most cost-effective manner possible. Since 2010, the number of people in the system and total spending on their services and supports has grown. Approximately 2300 people are now in the system, while the budget covering placements through the waiver has approached \$300 million dollars.

The transformation of the system of the past to that of the future was occurring over the period covered in this report. Whereas the system of the early 2000s was smaller, and people who lived at Forest Haven (*Evans* class members) were a more sizable proportion of the overall system; (in 2003, approximately 1600 people of which over eight hundred were *Evans* class members), the system now consists of approximately 2300 people and fewer than four hundred class members remain. The data in this report show that the system is becoming one dominated by young African American males. Many of these young men come to the DDS system through the Department of Youth Rehabilitation Services (DYRS) and the Child and Family Services Administration (CFSA). The service preferences and needs of this group are distinctly different from those of earlier years. Medical complexity, prior institutionalization and lack of community integration defined many people who lived in congregate settings in the system of the past. At the same time, many people then lived at home, where few services were available to gain employment, and other life enriching activities. Now many people entering the system bring with them involvement with the mental health and criminal justice systems, complex family dynamics but significant community involvement.

Two other factors will shape the contours of change going forward: rebalancing the dynamics between users of services, providers, and the government due to the mandates included in the New Settings Rules issued by the Center for Medicaid & Medicare Services (CMS) in 2014, and changes to eligibility for DDS services introduced in the Council this summer. If a final vote on the bill in the coming year is successful, expanding eligibility to all people with developmental disabilities not just intellectual disabilities will significantly broaden the need for diverse types or levels of support. It is unclear whether the providers currently in the system possess the skills and flexibility needed to adapt to the coming changes as they will most certainly need to do. So, we hope this report about the past begins a much-needed discussion about the future.

INTRODUCTION

This report of demographic and incident data was made possible by collaboration between Quality Trust for Individuals with Disabilities (Quality Trust) and the Department on Disability Services (DDS) as well as research and analysis by a Georgetown University Pre-Med intern and a PhD data analyst. In this report we delve deeply into the demographic makeup of the system of services and supports provided to people who experience intellectual and other developmental disabilities in the District of Columbia, and we also cover the incidents and investigations that occurred between years FY 2011 and 2020. That decade was marked by several significant developments. Although the *Evans* case; the legal action filed on behalf of residents of Forest Haven was not concluded until January of 2017, initiatives undertaken prior to and during this decade provided the improvements necessary to conclude the case. Leading up to this time, the most significant system improvement was the implementation of the first substantial HCBS (Home and Community Based Services) Medicaid waiver which took effect in the fall of 2007. Before then the District of Columbia had failed to organize a structure through which large scale drawdowns of FMAP (Federal Matching Assistance Percentage) could be achieved. For the District of Columbia, FMAP covers 70% of total Medicaid expenditures. By 2010, the migration of local and federal spending into the budget of the Department on Disability Services; the implementing agency in DC, was well underway. As a result, the migration away from the ICF/IDD (Intermediate Care Facility for Persons with Intellectual & Developmental Disabilities) program to waiver funded services could be achieved in the most cost-effective manner possible. Capturing maximum Medicaid dollars for least restrictive placements was not the only change to the landscape. Slowly and incrementally the demographic characteristics of the people supported in the system also changed. A steady but small number of people have entered the system each

year through the Department of Youth Rehabilitation Services (DYRS) and the Child and Family Services Administration (CFSA), and significant effort was put into returning home those people who sought or were directed to out of state placements. At the same time, the number of *Evans* class members within the system was also slowly declining due to death. The transformation of the system of the past to that of the future was occurring over the period covered in this report. Whereas the system of the early 2000s was smaller, and people who resided at Forest Haven were a more outside proportion of the overall system; (in 2003, approximately 1600 people of which over eight hundred were *Evans* class members), now the system has approximately 2300 people and fewer than four hundred class members. The data in this report show that the system is becoming one dominated by young African American males. As noted, some but not all those young men come to the DDS system through DYRS and CFSA. The service preferences and needs of this group are distinctly different from those of earlier years.

Since 2010, the District of Columbia submitted several more waiver applications and amendments maximizing spending as the number of people receiving services has grown to approximately 2300 people, while the budget covering placements through the HCBS has approached \$300 million dollars.

Another key development in the way the system of services changed was the implementation of new Incident Management & Enforcement, (IMEU) policies and procedures. Prior to 2010, both the quantity and quality of incident investigations were deficient. Not only was the content of investigations insufficient to create confidence; the answers to the root cause of alleged incidents were ambiguous, and the lack of timely completion seriously called into question of the District's ability to protect people from harm. The 2010 policy introduced new incident definitions, changed the way incidents were investigated and by whom, and placed new

expectations for implementation of incident management and overall quality assurance on providers. Providers were tasked for the first time with hiring incident managers whose role was not only to formally report and investigate all Reportable and Serious Reportable Incidents, but also to track and trend the data created to develop harm reduction capacities within their organizations. In Fiscal Year 2022, the jury is still out regarding the ability of all providers to successfully conduct this mandate. As with so many facets of the DC system, results vary by provider. One specific category of incident on which data has been gathered and shared with Quality Trust over this period is Unplanned Emergency Inpatient Hospitalizations (UEIH), (prior to 2010 these were called Emergency Inpatient Hospitalizations). There are of course many other means by which elements of the overall provision of healthcare can be measured, but most of that data is collected by and remains inside DDS. Since DDS does not produce public reports, the public is left without reliable information outside that which Quality Trust has produced through our annual monitoring reports. When developing our analytical process for this report we wondered if we could utilize incident data, and specifically UEIH data to answer one or both of the following questions. Did the occurrence of UEIH's diminish during the period between 2010-2017 when so much emphasis was placed on improving healthcare services and supports, and if so, did the data indicate a slippage after 2017 when the case was concluded as some people speculated might occur at the time? The data we present in this report does not support either scenario because there has been no discernable change in the data around UEIHs throughout the entire ten-year period. As it always has been, going to the hospital in an unplanned manner remains the dominant incident experienced by people receiving DDS services and supports.

The overall objectives of this report are to:

- describe the demographic makeup up of the people receiving services and supports during the period 2011-2020
- document and analyze the incidents that occurred during those years, and,
- spark discussion among stakeholders as to what the system of the future should be and what steps will be required to get there.

We chose this timeframe because beginning in FY 2010 the parties in the Evans litigation, a case that was entering its 32nd year had agreed to enter a new phase of partnership in the hope that doing so could more quickly bring about system improvement significant enough to settle the case. Quality Trust, working directly with the Court Monitor would monitor using a tool negotiated by the parties. The tool was designed to measure progress in satisfying the court orders that remained at that time. Two of the most widely discussed, monitored, and struggled with outcomes involved several aspects of the provision of basic healthcare and investigations of incidents; especially as that could be construed to relate to protection from harm. Although contained in more than one court order, the basic issue was whether the District of Columbia, through DDS, DHCF and DOH had created a systemwide combination of improved nursing and healthcare supports, and investigation and remediation of incidents and processes for reliably monitoring those improvements. Reform effort after reform effort by consultant after consultant, were launched to create reliable, sustainable improvement.

Since its inception in 2002, the Quality Trust has advocated for and monitored the services and supports provided to people who experience intellectual and other developmental disabilities in the District of Columbia. We have been using our current approach since the 2010 inception of Joint Monitoring within the Evans case. In that process we were involved, along with the Court Monitor in monitoring both class and non-class members. Since the conclusion of the Evans case, in January of 2017, we have been the primary external system monitor. Having completed eleven years of monitoring reports containing countless observations, conclusions, and recommendations, and witnessing the slow transformation of the system we sought to produce a report covering the past ten years. What follows is that report. It is based on demographic and incident data covering the years FY 2011 to 2020. We hope to provide with as much detail as the data allows, an analysis of the number, type, and final investigatory disposition of the 11,000+ Serious Reportable Incidents that have been generated during that time. We note trends in this incident data, and where supply conclusions that can be made as a result. Unfortunately, while this data is helpful in developing insight into some characteristics of the people who have made up the service system over these ten years, it does not provide sufficient detail to allow us to make causal connections or offer specific recommendations on a whole host of issues. We hope it does provide an opening for further dialogue that will be carried forward by DDS, providers, families, and all others who have a stake in understanding and improving the system of services and supports provided to people with intellectual and other developmental disabilities in the future.

Two other factors will shape the contours of change going forward: rebalancing the dynamics between users of services, providers, and the government due to the mandates included in the

New Settings Rules issued by CMS in 2014, and changes to eligibility for DDS services introduced in the City Council. If a final vote on the bill in the coming year is successful, expanding eligibility to all people with developmental disabilities, not just intellectual disabilities will significantly broaden the needs for distinct types or levels of support. It is unclear whether the providers currently in the system have the skills and flexibility needed to adapt to the coming changes as they will most certainly need to do.

We hope the data in our report and the conclusions we have drawn will encourage stakeholders to begin a dialogue about what the system of the future should look like, and how best to move from where we have been to where we need to go.

METHODOLOGY

This report offers insights that only analysis of substantial amounts of data over extended periods of time can provide. Before we delve into the data analysis, we need to explain the methodological techniques used to develop graphs, charts, and tables included in this report. These are categorized into four general areas and described below.

Data Extraction and Transfer

Data sources are different. DDS is the source of real time data for incidents, so the incident dataset is therefore extracted from their website since 2011. The data is presented on a quarterly basis for all Serious Reportable Incident details from 2011 to 2020 in Excel macro-enabled format. There are fourteen columns in the dataset. These include, Incident Number, Individual, Individual Type, Incident Type, Incident Type Desc, Incident Date, IMEU Accepted Date, Investigation Due Date, Incident Close Date, Incident Status, Disposition, IMEU Investigator, Compliance Specialist and Provider. The second type of dataset includes demographic information for the people in the system since Fiscal Year 2011. This data consists of First name, Last name, Date of birth, Age, Race, Gender, Residential provider, and Facility type.

Data Cleaning and Pre-Processing

The first step in the data cleaning and pre-process was to extract the dataset files from the source and archive or save them in a proper location. The next step was to uniformly rename or edit the files because they are stored in a folder for each year where each year contains four Excel files for each quarter. The third step was to check the structure and content of each quarter to ensure they contained equal number and name of column headers. After checking all tables of quarterly incident reports, extra columns were deleted, and new columns were added when needed before

they were imported to the data model. A specific program called Power Query uses important queries and syntax to perform cleaning, processing, transformation, and extraction, for all analytical tasks. The final data organizational task involving the incident data was to join or merge the incident dataset with the demographic dataset using individual names. Individual names were typed differently between the two datasets which presented us with a big challenge when we ran programs for matching data sets. In the end we used Power Query's "Merge Queries" function which enabled us to match and then merge columns into a single table. With this approach we were able to achieve full matches between the incident dataset and demographic dataset.

Data Analysis

Both descriptive as well as inferential analysis have been conducted in the preparation of this report. The first stage was to conduct descriptive analysis on the individual datasets. Totals, frequencies, percentages, mean, median and mode are some of the simple statistical summaries. Using the ten years of data, predictions (inferences) were made for incidents that would be expected to happen after two years in 2021 and 2022. Simple regression modeling is used to predict the number of incidents over time, where the number of each individual incident type will rest at a dependent variable and incident dates will be projected as an independent variable to predict the number of incidents either on a quarterly or daily basis. Due to limitation of time, the inferential data analysis results will be included in the next revised report.

Data Visualization

Graphs such as bar chart, line chart, pie chart, and others have been used to illustrate some of the time series and categorical variables in the data. Excel is the primary tool to visualize most of the graphs and tables. An interactive and dynamic dashboard in Excel is used to show the changes over time and among distinct categories.

RESULTS AND DISCUSSION

Who Made Up the “System?”

Between FY 2011 and FY 2020, we were able to confirm that 3,099 people received at least some kind of support from the DC Developmental Disabilities Administration (DDA). The number of people who are in the system now and actively receiving services from DDA are 2,334. Figure 1 shows the number of service recipients over time from 2011 to 2020. The number of people has increased at a rate of 1.4 percent per year. The maximum number of people was recorded in 2019. The reason for the fluctuations in the number of service recipients over time will be discussed later in the incident analysis section.

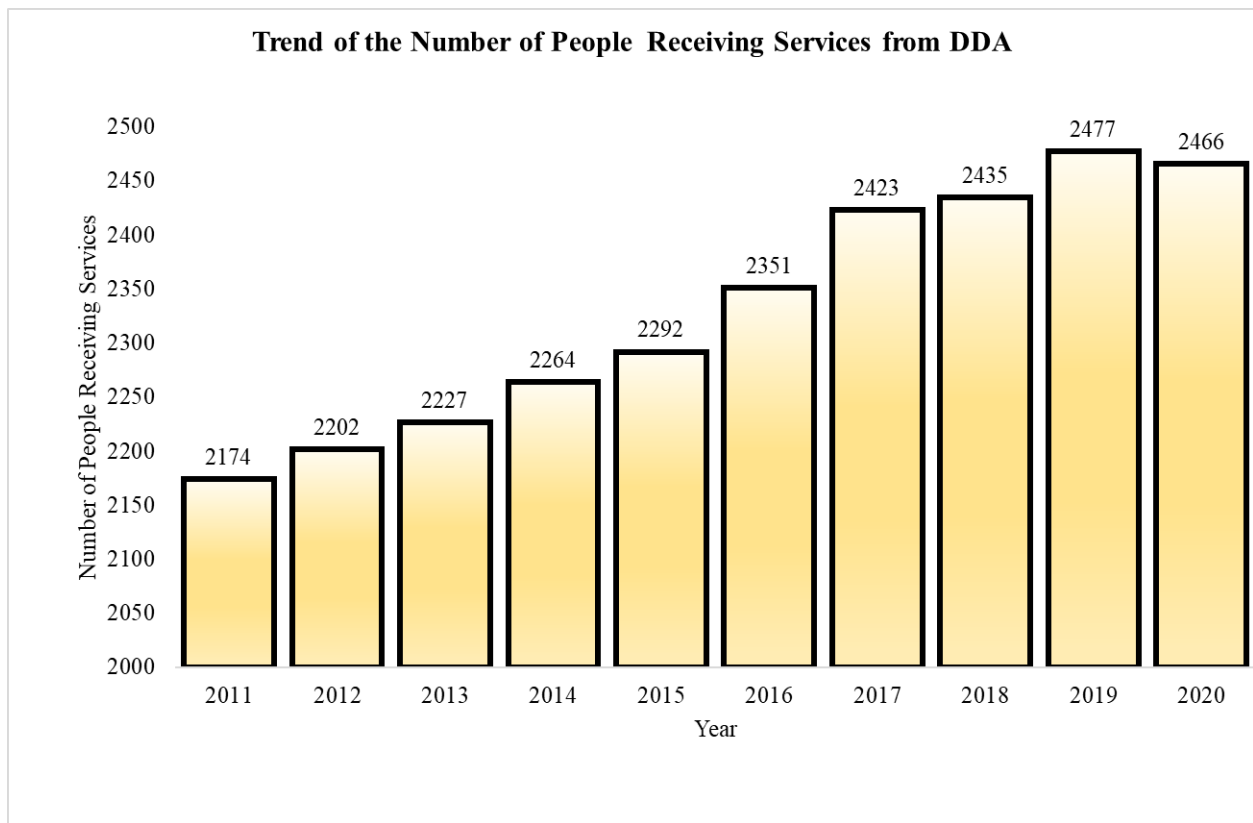


Figure 1. Trend of the number of people receiving services from DDA

Table 1 shows how the number of service recipients grew over ten years. DDA admits on average 107 new service recipients every year but an average of seventy-three individuals have left the system each year. An average of four people left the system after receiving supports for only for one year since 2012. A total of 670 individuals have exited from the system from 2011 to 2020. On the other hand, column five of Table 1 shows the number of individuals who have continually received services from DDA from 2011 to 2020; a total of 2466 people.

Table 1. The Number of admissions and exits of people receiving service from DDS/DDA

Year	New Service Recipients	Exited at Entry Year	Exited Total Service Recipients	Active Recipients as of 2020 from each Year Entry	Cumulative Active Service Recipients
2011	2174	85	85	1675	2,174
2012	113	9	79	75	2,202
2013	104	3	70	73	2,227
2014	107	2	64	81	2,264
2015	92	2	67	77	2,292
2016	126	2	65	111	2,351
2017	137	4	80	114	2,423
2018	92	3	69	76	2,435
2019	111	7	91	104	2,477
2020	80			80	2,466
	3136	117	670	2,466	

Demographic Composition of DDA Service Recipients

The unique number of people in the system who received and who continue to receive services from DDA from 2011 to 2020 is 3,099. The demographic composition of these people is noted in Table 2 below.

Table 2. Demographic composition of unique number of all service recipients

Category	Number of People	Percentage of People
Gender		
Female	1,188	38%
Male	1,911	62%
Total	3,099	100%
Age		
20 or Younger	162	5%
20 - 29	1,141	37%
30 - 39	425	14%
40 - 49	450	15%
50 - 59	541	17%
60 - 69	275	9%
70 - 79	76	2%
80 or Older	29	1%
Total	3,099	100%
Race		
African American	2,581	83%
Caucasian	203	7%
Other	118	4%
(blank)	91	3%
Hispanic	76	2%
Unknown	16	1%
Asian	10	0%
Native American	4	0%
Total	3,099	100%

Gender

The proportion of males (61%) to females (39%) has remained the same almost every year.

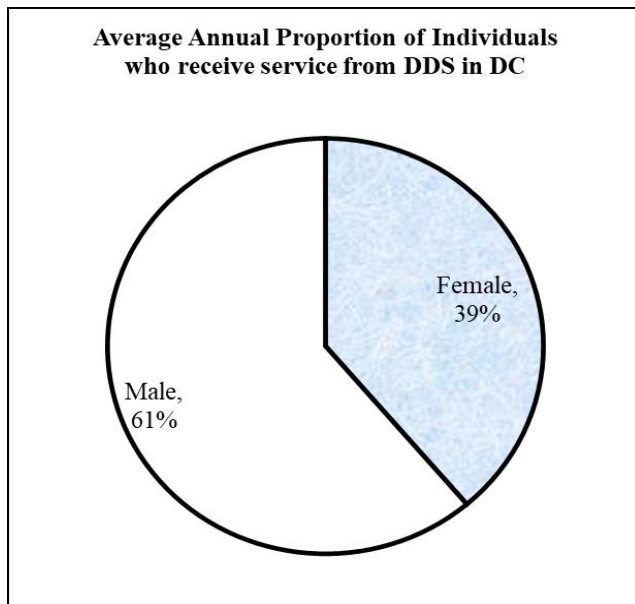


Figure 2. Gender composition of people receiving service from DDA

Age

Age is another demographic factor that shows a relative difference in who makes up the system of services and supports in the District of Columbia. For example, while 83% of recipients are between the ages 20-59, the largest cohort are those people between the ages of 20-29 (37%).

The number of men is almost twice that of women within this same group of young people. To that extent, it can be argued that the system of the future 20-30 years will be dominated by young men. The next largest number of people are 50 to 59 years of age. Here again, the number of men is greater than women. This group is dominated by people who have been receiving services of one kind or another for several years of their adult life. It is vitally important that DDS/DDA create service models flexible enough to appeal to and effectively support both groups. It is

equally important that the providers who currently operate in the District of Columbia begin to shift their overall approach to providing services and supports so they can meet the needs of the younger people who will make up the system of the future.

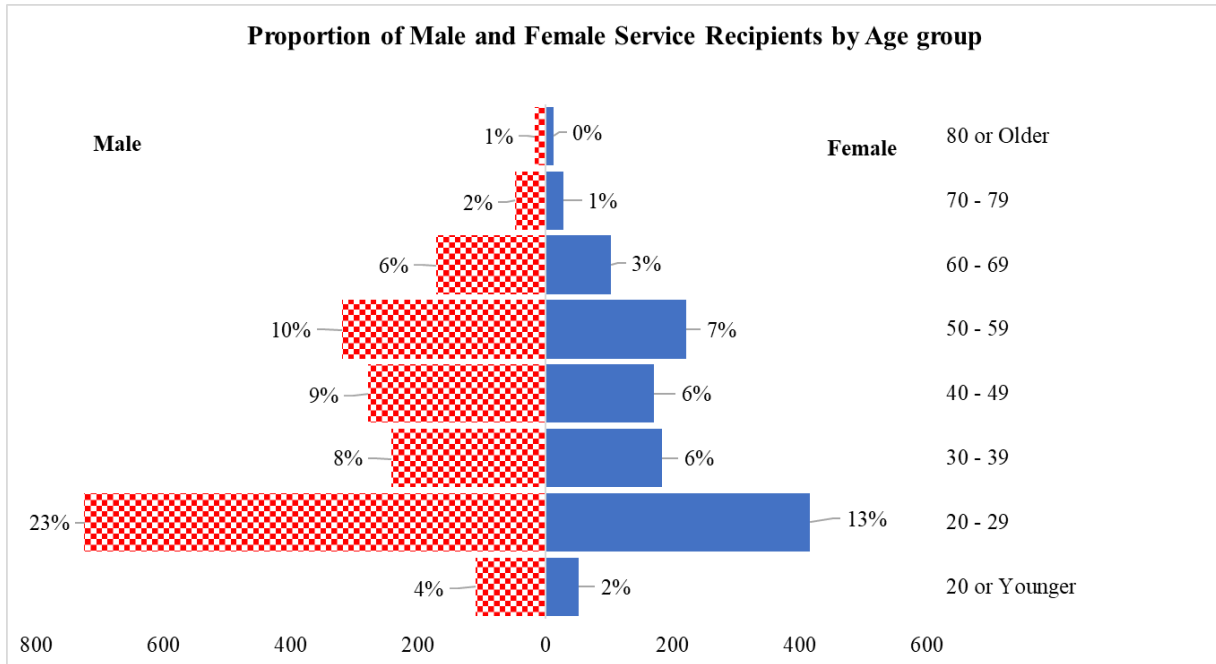


Figure 3. Proportion of total men and women who received services by age group since 2011

As Figure 3 above shows young service recipients in age group from 20 to 29 years are mostly men and they are almost twice as large a group as any of their counterparts.

Race

The District of Columbia is an ethnically and racially diverse community. According to the 2010 Census data, the racial and ethnic trends between D.C. and the U.S. are notable with the district’s high proportion of African American residents (51%) while Caucasians comprise (38.5%)¹ of residents. It is statistically significant then that African Americans make up 83% of service

¹ Charles Moseley, K. Charlie Lakin. (2011). Assessment and Analysis of the Service Needs of Washington, D.C. Residents with Intellectual and Developmental Disabilities. *For Washington, D.C. DDS, NASDDDS*, 59(6), 571-583.

recipients while only 7% of Caucasians do. Table 2 shows the proportion of race for the entire number of people for the ten-year period.

Figure 4 below demonstrates that African Americans far outnumber all other races of people in the system in DC. The gender proportion of those African American services recipients is like the gender proportion of all people within the system, however. This finding would seem to demonstrate that race has more influence on the proportion of people in services than that of gender or any other factors.

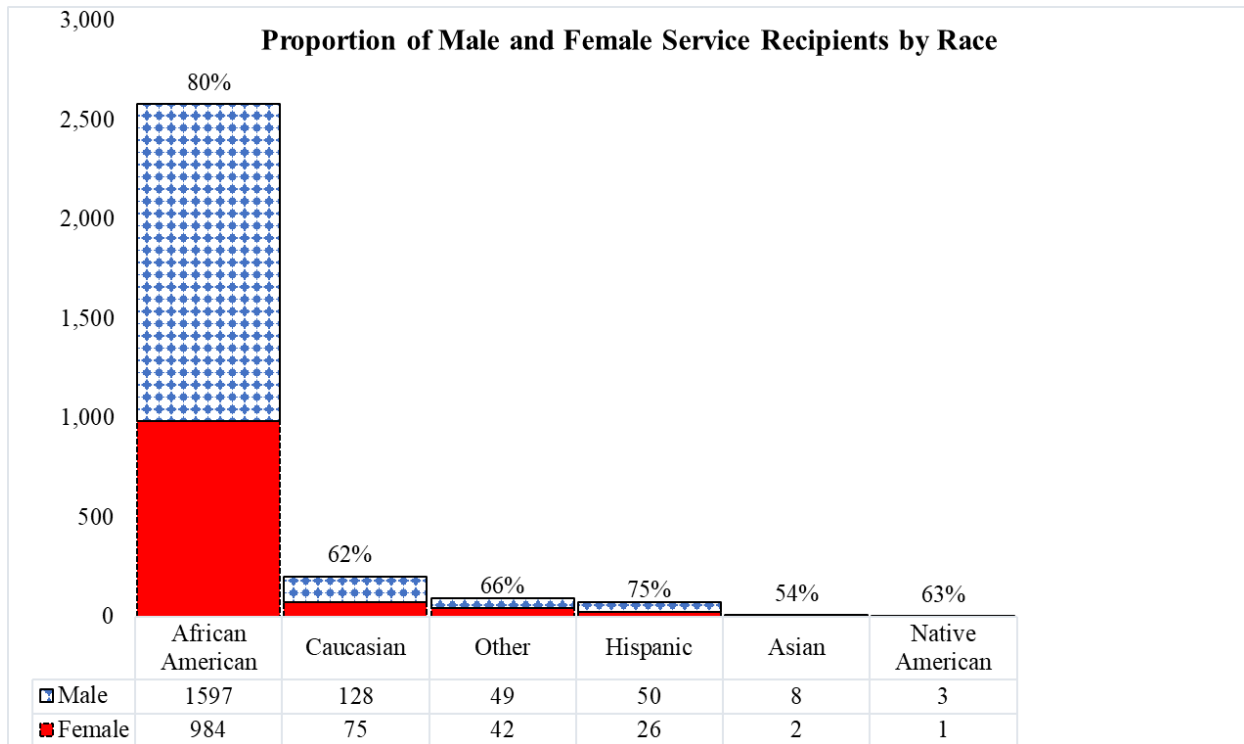


Figure 4. The proportion of people by race and gender of the total service recipients since 2011

Residential Settings Type

The 3,099 service recipients over the ten-year period have been supported in 3392 unique residential placements. That is, one person can, and often has utilized more than one type of service, through one or more different providers. Even though 2776 (90%) people live in one

residential placement, 269 (9%) have been in two placements and the rest; 54 (1%) have been in three to five residential placements/facility types. Out of the 3,392 residential placements used over the ten years since 2011, 1,632 (48%) are Natural Home, 812 (24%) are Supported Living, 408 (12%) are Residential Habilitation, 199 (6%) are Intermediate Care Facility, 100 (3%) are Host Home, 29 (1%) of the placements were Independent Living and finally Out of State Placements were 34 (1%) of total placements.

Figure 5 shows Natural Home and Supported Living are the most dominant residential placement types throughout the ten-year period, and both increase over time. The third highest setting type is Intermediate Care Facility, but it shows a slight decline every year since 2011. Other settings such as Residential Habilitation, Host Home, Out of State and Independent living were the least frequently used residential setting type over the last ten years.

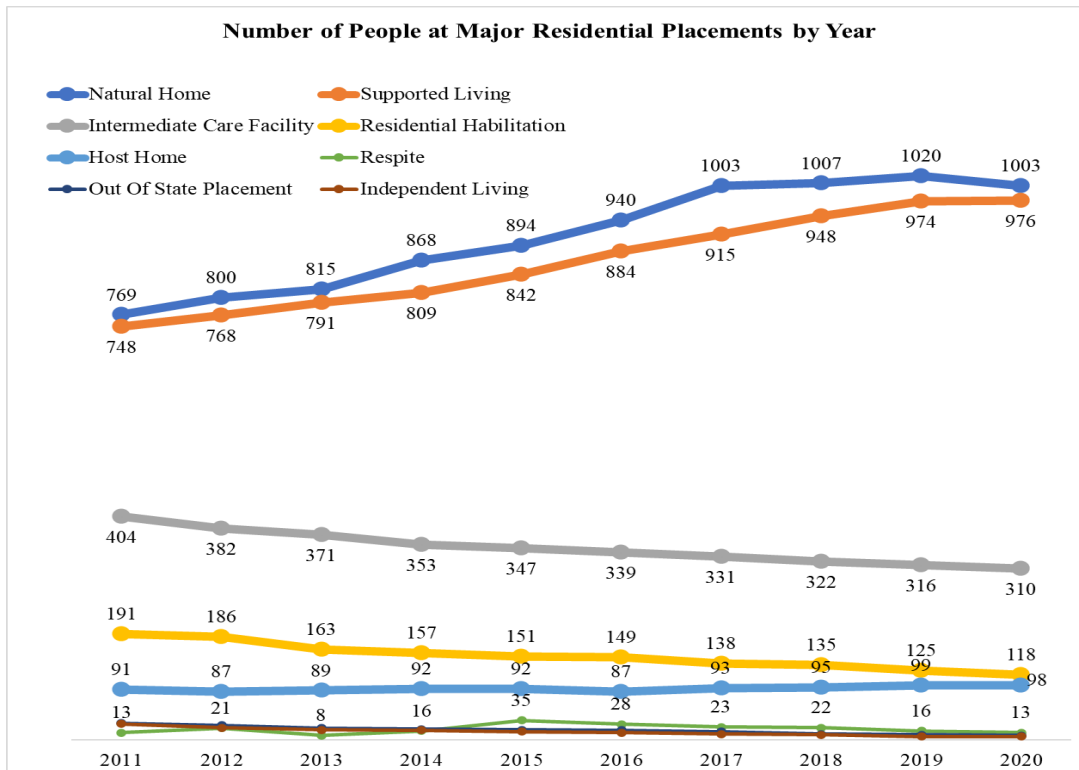


Figure 5. Visualization of the yearly trend of the number of residential placements of service recipients from 2011 to 2020.

The percentage breakdown of residential placements each year over the period of the report can be shown in Table 3 below.

Table 3. The breakdown of residential placements over the period of the report

Residential Placements	Year										Total
	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	
Natural Home	33%	34%	35%	36%	37%	37%	39%	39%	39%	39%	37%
Supported Living	32%	33%	34%	34%	34%	35%	35%	37%	37%	37%	35%
Intermediate Care Facility	17%	16%	16%	15%	14%	13%	13%	12%	12%	12%	14%
Residential Habilitation	8%	8%	7%	7%	6%	6%	5%	5%	5%	5%	6%
Host Home	4%	4%	4%	4%	4%	3%	4%	4%	4%	4%	4%
Respite	1%	1%	0%	1%	1%	1%	1%	1%	1%	0%	1%
Out Of State Placement	1%	1%	1%	1%	1%	1%	1%	0%	0%	0%	1%
Independent Living	1%	1%	1%	1%	1%	1%	0%	0%	0%	0%	1%
Other facility Types	3%	3%	3%	2%	2%	3%	2%	2%	2%	3%	2%
Total	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Service Providers

Out of the 1,975 total providers supporting the 3,099 persons in the system from 2011 to 2020, 1,865 (94.4%) have been supporting only one person. The remainder have supported the same person more than once or multiple people in different residential placements. The most probable explanation for the considerable number of single person placements is that Natural Homes are the dominant residential service type, as shown in Table 3 above.

Table 4. The top ten service providers and their corresponding placements from 2011 to 2020

No	Service Providers	Frequency of Use by Service Recipients	The Most Frequently Used Placement by Service Providers	The Frequency of Use	Percentage of Use
1	Wholistic Habilitative Services	843	Intermediate Care Facility	411	48.24%
2	National Children's Center	840	Supported Living	584	68.79%
3	Community Multi-Services	833	Supported Living	407	48.74%
4	St. John's Community Services	815	Supported Living	815	100.00%
5	RCM of Washington	792	Intermediate Care Facility	358	44.14%
6	Metro Homes, Inc.	777	Intermediate Care Facility	443	56.65%
7	DC Healthcare, Inc.	733	Intermediate Care Facility	494	66.67%
8	Innovative Life Solutions	642	Intermediate Care Facility	298	45.57%
9	My Own Place Inc	592	Supported Living	493	82.30%
10	Multi-Therapeutic Services	590	Residential Habilitation	307	50.08%

ANALYSIS OF INCIDENT AND INVESTIGATION DATA

People with Incidents

The ten-year proportion of people with and without incidents are shown in Table 5 below.

Table 5. The number of people who received services with and without incidents over the years.

Year	People With Incidents	People Without Incidents	Percentage of People With Incidents	Total Number of People
2011	616	1,558	28%	2,174
2012	624	1,578	28%	2,202
2013	587	1,640	26%	2,227
2014	633	1,631	28%	2,264
2015	713	1,579	31%	2,292
2016	696	1,655	30%	2,351
2017	720	1,703	30%	2,423
2018	700	1,735	29%	2,435
2019	555	1,922	22%	2,477
2020	674	1,792	27%	2,466
Total	6,518	16,793	28%	23,311

A clear take away from this table is that between 22-31% of people experienced at least one incident every year. The consistency of incidents incurred, and the proportion of total incidents generated is striking, and an explanation for that regularity escapes us except to say that overall, incident data for this 10-year period is eerily consistent. This is especially noteworthy when one considers that the number of people receiving services has consistently risen. This finding should spur DDS/DDA to study this data in further detail, making its conclusions known to stakeholders and advocates.

Number of People and Incidents

Of the 3,099 people who have been receiving services and supports funded through DDS/DDA, 2,049 have experienced a total of 11,648 incidents between 2011 and 2020. The highest incident per person was ninety-eight, but most people, 1247 (61%), have experienced from three to twenty incidents. As shown in Table 6, 389 (17%) people have experienced only one incident through 2020. 1050 (33.9%), people have never experienced an incident since 2011 (3099 minus 2049).

Table 6. The frequency of incidents per person

Number of Incidents per person	Number of People	Percentage of All People
98	1	<1%
86	1	<1%
40 - 60	7	0%
20 - 40	58	3%
3 - 20	1247	61%
2	346	17%
1	389	19%
11,648	2049	100%

Table 7 below illustrates the demographic compositions of service recipients of DDA who have reported at least one incident since 2011.

Table 7. Demographic distribution of service recipients who experienced at least one incident

Category	Number of People	Percentage of All People
Gender		
Female	796	39%
Male	1253	61%
Total	2049	100%
Individual Type		
Class Members (Evans)	525	26%
Non-Class Members	1524	74%
Total	2049	100%
Age		
20 or Younger	67	3%
20 - 29	556	27%
30 - 39	291	14%
40 - 49	362	18%
50 - 59	437	21%
60 - 69	247	12%
70 - 79	66	3%
80 or Older	23	1%
Total	2049	100%
Race		
African American	1745	85%
Caucasian	168	8%
Other	44	2%
(blank)	40	2%
Hispanic	39	2%
Unknown	6	0%
Asian	4	0%
Native American	3	0%
Total	2049	100%

Incident Type Description

When developing our analytical process for this report we wondered if we could utilize incident data, and specifically UEIH data to answer one or both of the following questions. Did the occurrence of UEIHs diminish during the period between 2011 and 2017, when the case was concluded? And, as some speculated at the time did occurrences increase after 2017? What we found is that the total number of incidents increased at a rate of (6%) during the years leading up to 2017, and then dropped by the same (6%) since. Figure 5 shows 2017 was the year with the highest incidents (1306) within the ten-year period since 2011. So, it can be argued that according to our data more incidents were reported in the final year of the *Evans* litigation. As the next chart shows, however regardless of whether more or fewer incidents were reported the number of UEIHs has absolutely increased and remained the dominant incident category in proportional terms.

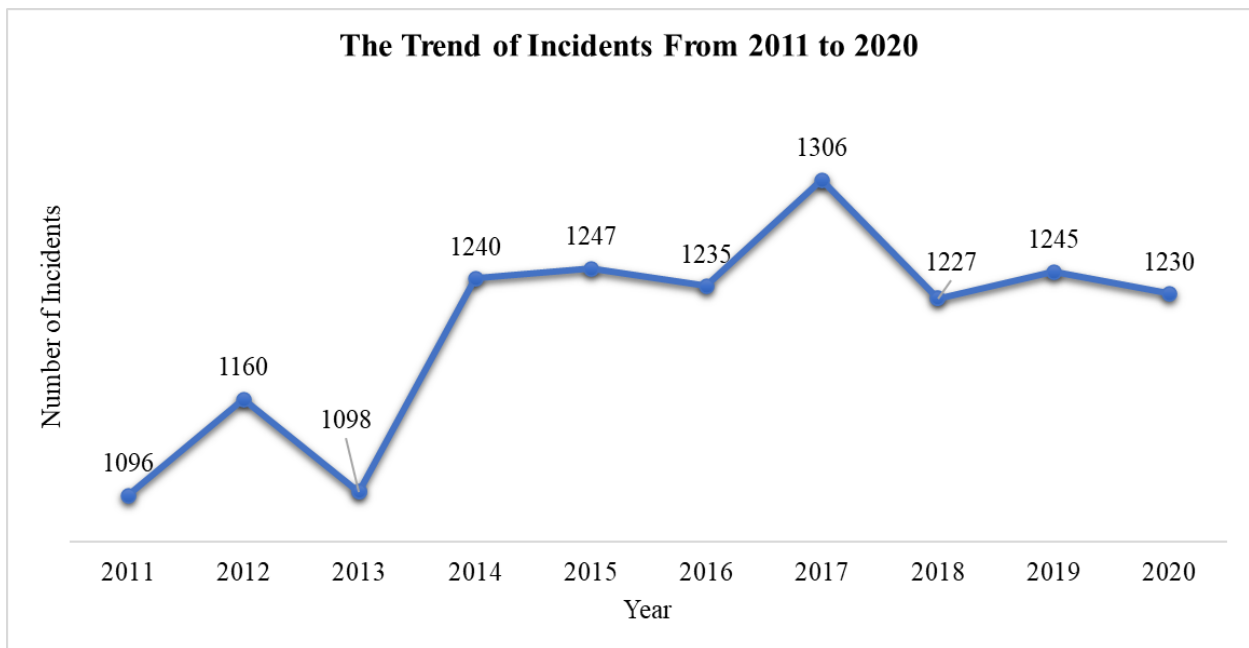


Figure 6. Trends of the number of UEIH over 10 years period from 2011 to 2019.??

The data shows that the most dominant incident type is Emergency Inpatient Hospitalization/ Unplanned Emergency Inpatient Hospitalizations (EIH/UEIH) (44%). Despite some slight fluctuations, the number has increased since 2011 over the ten-year period. The next most frequent incident was Neglect, which has decreased slightly over the ten-year period. Figure 2 shows the trend in the number of most frequent incident since 2011.

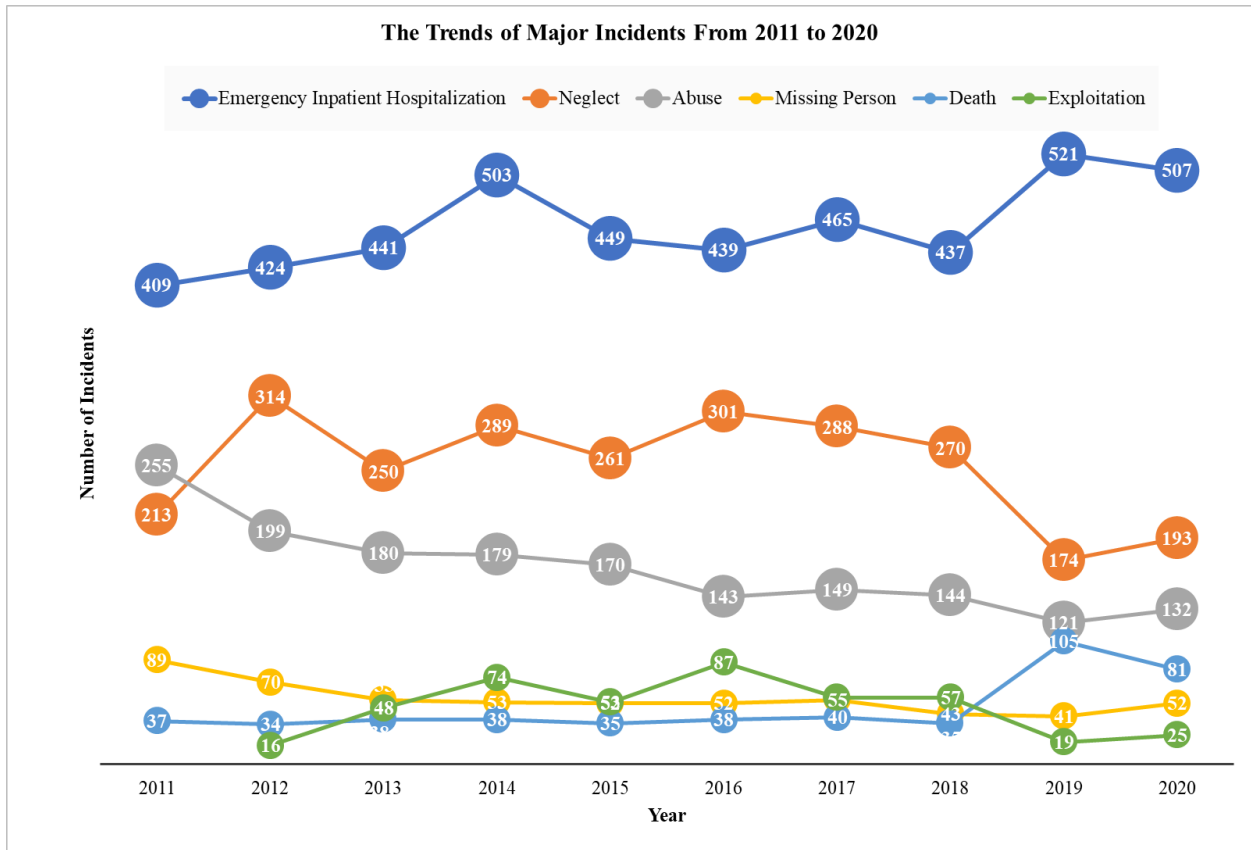


Figure 7. The trend of the number of major incidents from 2011 to 2020

Trend of UEIH Incidents

The most frequent incident is Unplanned/Emergency Inpatient Hospitalization (EIH/UEIH).

Here we see the increase since 2011, except some swings in 2014. Quarter two of 2017 involved the second highest number of incidents next to quarter three of 2014.

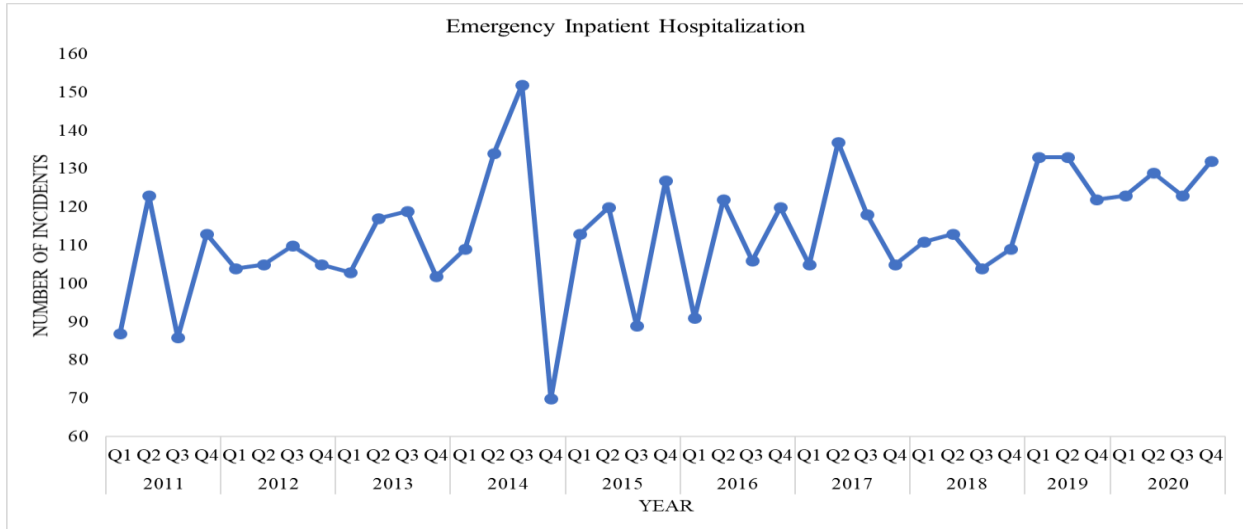


Figure 8. Quarterly trend of EIH from 2011 to 2020

UEIH by Gender and Time

As shown in Figure 8 below, the proportion of incidents experienced by males has shown a continuous increase between 2011-2016. It fluctuates for the last five years and reached 56 percent in 2020. We estimate that the number could reach 300 UEIH incidents in the coming years. Women have had an average of two hundred unplanned hospitalizations each year from 2011 to 2020.

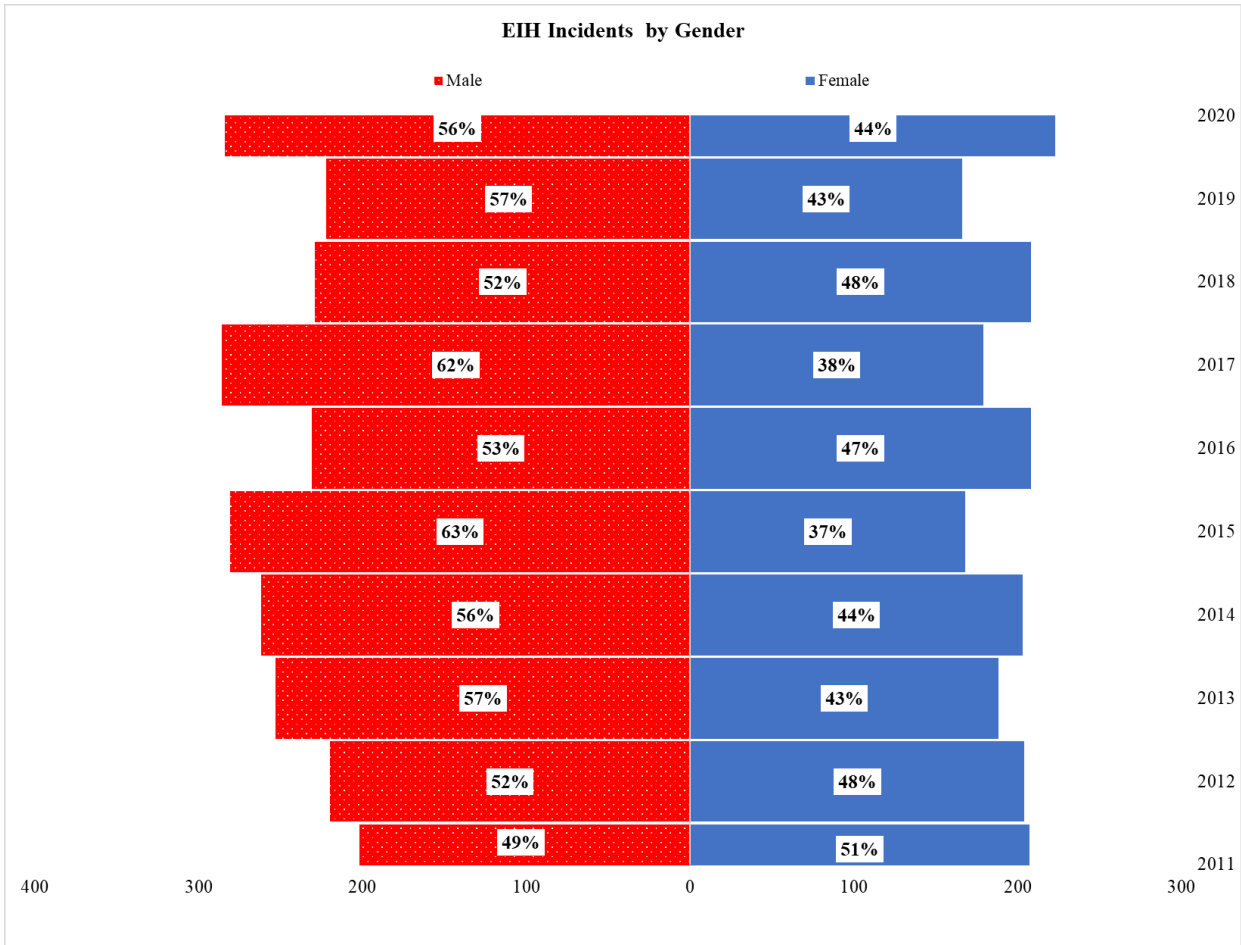


Figure 9. The percentage of UEIH incidents by gender and over time.

UEIH by Person for Evans Class/Non-Class Members

As shown in the Table 7 before, 525 (26%) people who have faced at least one incident since 2011 are Evans Class members. We were not able to capture data pertaining to the proportion of Class members in relation to all people in the system over the ten years. We would need to receive that specific data to complete that analysis. We can say however from the data we were able to capture that the number of class members experiencing incidents over the years was/is in keeping with their proportion of overall service system membership. The one exception to that is

2020, when their proportion of incidents was higher than their proportion of overall system members.

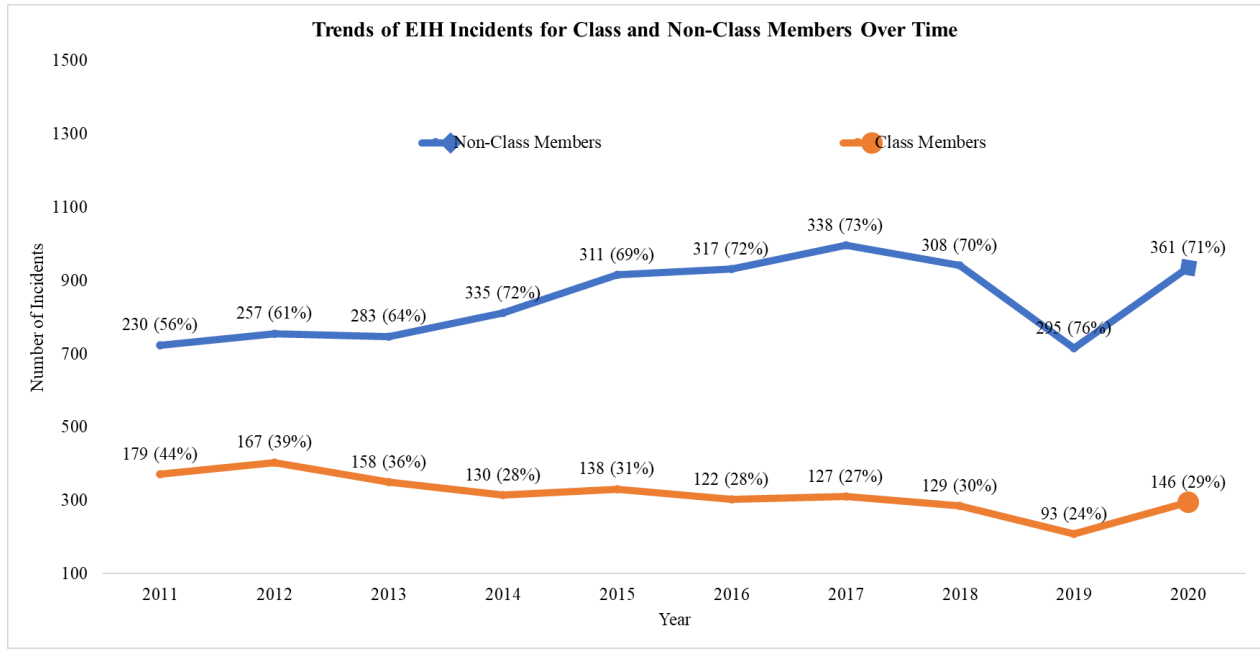


Figure 10. The trend of UEIH incidents experienced by Class and Non-Class members since 2011.

Death by Gender, Person over Time

The number of deaths did not decline over time throughout the ten-year period for both class members and genders. Years 2019 and 2020 have shown a peak in the number of deaths which was due to COVID-19, there was an increase that was outside of COVID, which we spoke about in our annual monitoring report last year. We have more analysis about this issue in this year’s monitoring report. Both reports can be found on our webpage at [Reports & Publications | Quality Trust \(dqualitytrust.org\)](https://www.dqualitytrust.org/Reports-Publications/Quality-Trust).

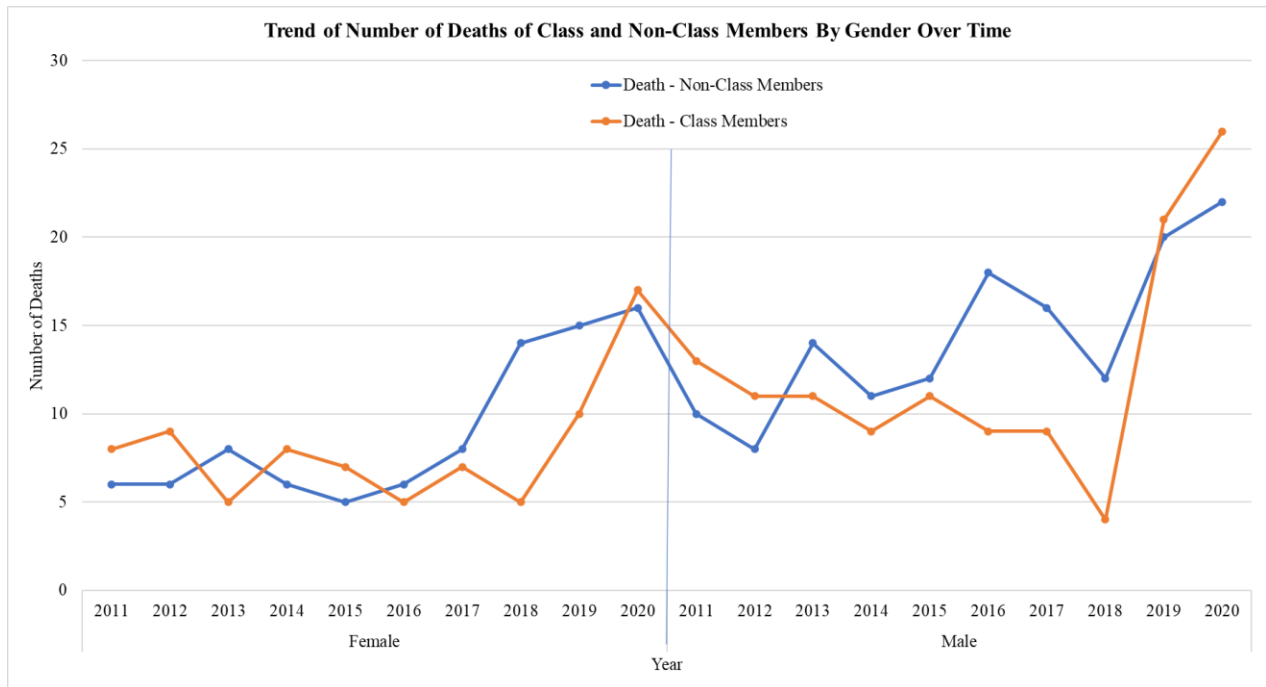


Figure 11. Trend in the number of deaths for female and male Class and Non-Class members over time

Dispositions of Incidents Over the Ten Years

After incidents are reported by service providers or others who observe what they believe to be an incident, they are assigned a number by the Immediate Response Committee (IRC). Once Serious Reportable Incidents are designated by a number, they are entered into the Incident Management & Investigation Unit (IMEU). Investigations are required to be closed within 45 days according to the policy in place since 2010. Finally, when the investigation is closed with dispositions and recommended. Figure 11 shows the trend of the top three dispositions taken from 2011 to 2020. Closing investigations with the disposition Resolved-No Abuse or Neglect has dramatically increased since 2013. The more definitive dispositions of substantiated or unsubstantiated have consistently decreased over time. We believe the explanation for this involves the number of staff within IMEU available to lead investigations. UEIHs are the most

numerous incidents. As level II incidents, providers primarily investigate them themselves. UEIH investigators then review the investigations and either approve, or request changes. We have been advocating for years that UEIH be elevated to level I, so that IMEU investigators lead the investigations. Doing so, who increase workloads by close to four hundred investigations per year. According to DDS/DDA leadership this increase would create a backlog of investigations which is why they remain level II.

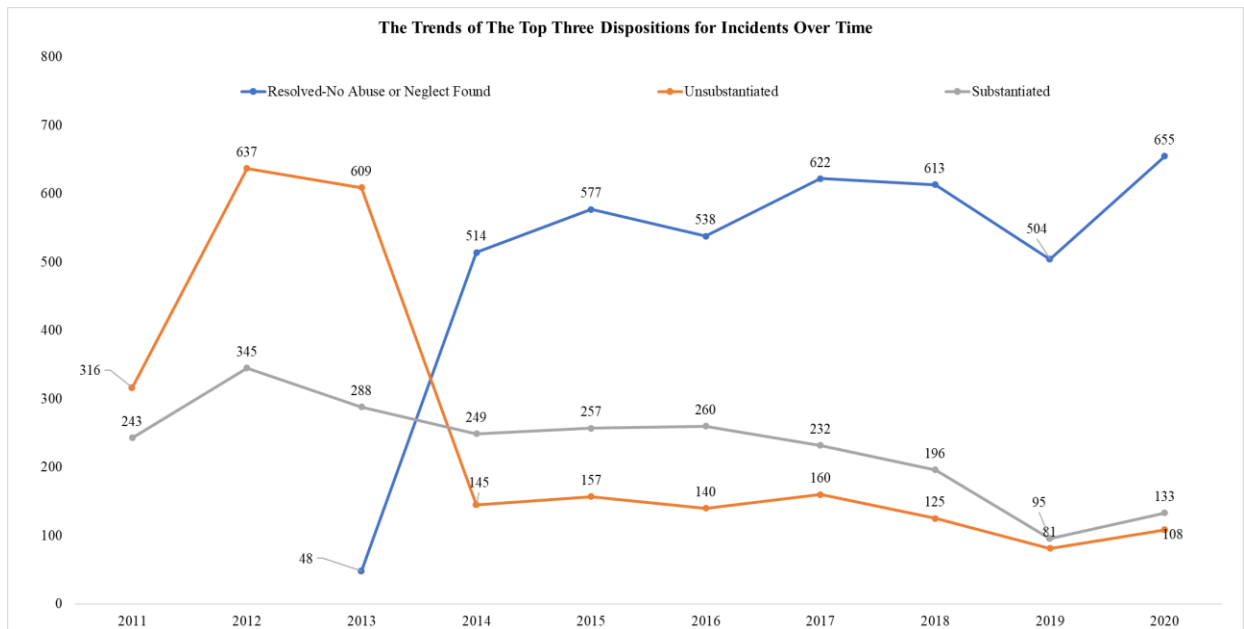


Figure 12. The number of dispositions taken for each incident over time since 2011

Table 8 below shows the composition of the total number of dispositions recommended for the incidents reported for the ten-year period.

Table 8. The distribution of dispositions for the total incidents between 2011 and 2020

Disposition Category	Frequency of Disposition	Percentage of the Disposition
Resolved-No Abuse or Neglect Found	4071	35%
Unsubstantiated	2478	21%
Substantiated	2298	20%
(blank)	986	8%

Inconclusive	680	6%
Administrative closure	608	5%
Substantiated for Neglect	468	4%
Substantiated for Abuse	35	0%
Unresolved- Upgraded to Allegation of Abuse, Neglect or Exploitation	23	0%
Substantiated for Exploitation	1	0%
Grand Total	11,648	100%

During the ten years reflected in this report there were 11,648 incidents recorded. The breakdown of types of dispositions taken for each incident type is as follows.

Table 9. Combination of the number of incidents and their corresponding dispositions during the ten-year period since 2011

Disposition/ Incident Type	Emergency Inpatient Hospitalization	Neglect	Abuse	Exploit ation	Missing Person	Serious Physical Injury	COVID -19	Total
Resolved-No Abuse or Neglect Found	2910	7	11	3	242	711	90	3997
Unsubstantiated	851	578	620	105	111	174		2454
Substantiated (blank)	64	1454	494	179	21	57		2270
Inconclusive	331	50	28	3	80	39		972
Administrative closure	51	133	328	82	12	62		668
Substantiated for Neglect	127	212	83	40	25	51	14	553
Substantiated for Abuse	70	47	48	18	57	149	2	398
	4	2	9	1		12		28
Grand Total	4408	2483	1621	431	548	1255	106	11340

The most probable disposition for EIH/UEIH incidents is Resolved- No Abuse Neglect found. In our Annual Monitoring Reports, we have written extensively about the causes and consequences of this trend. Please refer to any of our reports of the past six years for details. The reports can be found on our website at: [Reports & Publications | Quality Trust \(dcqualitytrust.org\)](https://www.dcqualitytrust.org/Reports-Publications) .

CONCLUSIONS

This report of incident data and the demographic makeup of the system of services and supports provided to people who experience intellectual and other developmental disabilities in the District of Columbia during Fiscal Years 2011-2020 was intended to provide the reader with basic knowledge of who made up the system over those years. We also sought, as much as possible given the data we had access to whether we could discern specific trends; improvements or slippage relating to DDS/DDA's ability to protect people from harm. Given the limitations of the data set we had we were unable to do that. The incident data we analyzed demonstrate a uniformity that is unchanged by external factors, or the passage of time; in this case ten years. As we noted, it is possible, and we hope that DDS/DDA has such data and has conducted their own analysis, as they have created and modified policies over the ten years. It is only through robust quality assurance measures required by CMS in the HCBS waiver and preferred by people using services that correctly interpret and analyze data trends that that impactful and long lasting the improvements can be made.

As 2021 turns to 2022, a system of services and supports informed by, but not fully recovered from the COVID-19 pandemic awaits the vitally important process of reimagination that DDS/DDA must make to drive the system of the future. We hope that by looking backwards in this report a long overdue dialogue between government, providers, and stakeholders regarding what kind of system is not only possible but preferred will be launched. Factors shaping the contours of change are rebalancing the dynamics between users of services, providers, and the government due to the mandates included in the New Settings Rules issued by CMS in 2014, and

changes to eligibility for DDS services pushed through the City Council. If a final vote on the bill in the coming year is successful, expanding eligibility to all people with developmental disabilities, not just intellectual disabilities will significantly expand the need for distinct types or levels of support. It is unclear whether the providers currently in the system possess the skills and flexibility needed to adapt to the coming changes as they will most certainly need to do.

We hope the data in our report and the conclusions we have drawn will encourage stakeholders to begin a dialogue about what the system of the future should look like, and how best to move from where we have been to where we need to go.