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CHARACTERISTICS OF MEDICARE BENEFICIARIES WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

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People with intellectual or developmental disabilities (IDD) experience poorer health outcomes than people without disability, in part due to more limited access to necessary health care (Havercamp & Scott, 2015; Krahn & Fox, 2014; Krahn et al., 2006). It is commonly accepted that to fully address these disparities there is a need to establish a public health surveillance system for tracking the incidence of IDD and identifying the characteristics that may affect their health (Krahn et al., 2010; USDHHS, Office of the Surgeon General, 2002). However, there are multiple challenges when it comes to administering surveys with people with IDD, such as maintaining confidentiality, communication process, obtaining accurate proxy reports, and overcoming stigmatization (Fox et al., 2015). Additionally, there is no standardized method or questions that can be used to identify the IDD population in in national surveys. Furthermore, creating a sampling frame that includes people with IDD can be difficult due to the relatively low population prevalence (Krahn et al., 2010; Fox et al, 2015; McDermott et al., 2018; Shireman et al., 2013; Phillips et al., 2019). Analyzing administrative claims data (e.g., Medicaid, Medicare, private health insurance) offers much promise as one integral approach in increasing understanding of the health of larger samples of people with IDD, in a sustainable way, that applies the principles that underlie successful surveillance systems: simplicity, brevity, and uniformity (Fox et al., 2015; Phillips et al., 2019).

Recent literature documents the success in using nationally representative surveys to study people with IDD. For example, Havercamp and Scott (2015) combined data from the Behavioral Risk Factor Surveillance System (BRFSS) with National Core Indicators (NCI) to compare people with IDD to adults with disability or no disability, regarding health outcomes and health care utilization. However, the sample produced by this combination of data was limited to a sample of adults receiving state Developmental Disabilities services and supports in one state, and, as a result the findings have limited generalizability. Similarly, several studies have used large nationally representative surveys (e.g. Medical Expenditures Panel Survey and National Health Interview Survey) to understand people with cognitive limitations (e.g. Reichard et al, 2011; Reichard & Stolzle, 2011; Reichard and Fox, 2013; Horner-Johnson et al, 2013). However, these studies identify people with cognitive limitations rather than IDD, based on a question that serves as a loose proxy for identifying people with IDD when used in combination with other survey questions; and, the cognitive limitations question also identifies people with other conditions (e.g. dementia, stroke, etc.) that do not meet the definitions of IDD. It is impossible to identify which of those in the sample have IDD and which do not, limiting the accuracy and representativeness of the information.

Several recent studies have provided some understanding about success of using administrative claims data and smaller nationally representative surveys to understand the prevalence, health outcomes, and health care access of subpopulations of people with IDD. McDermott et al., (2018) recently used Medicaid diagnostic codes in administrative claims data to describe demographics and other characteristics of beneficiaries with IDD from five states (DE, IA, MA, NY, and SC) who were enrolled in Medicaid for at least one calendar year from 2008 to 2013. Another recent study used the same method with all-payer claims data from 2010 to 2014 to examine all New Hampshire adults with IDD who were covered by Medicaid or private insurance. This study was the first to show that examining all-payer claims data is a feasible method for state level surveillance of people with IDD (Phillips et al., 2019). In addition, Royer et al., (2014) linked one state’s Medicaid claims data with other state data systems to understand a subpopulation with rare conditions. Others have also used diagnostic codes in Medicaid and Medicare subpopulations to conduct surveillance activities regarding people with IDD about health care utilization and expenditures (Shireman et al., 2013), emergency department and inpatient use (McDermott et al., 2015), and quality of care (Shireman et al., 2010). Using Medicaid administrative claims data for research has several known limitations (i.e., complexity, coverage restrictions, generalizability)(Riley, 2009); but at the state level, or combined across several states or nationally, this method can provide a great deal of information about beneficiaries with IDD supported by this type of health insurance.

Until we can establish a broader public health surveillance system for people with IDD, these recent studies demonstrate the greatest promise of using administrative claims data for understanding the health of a substantial number of people with IDD. Each of these studies provides us with valuable evidence of the unique strength and potential of its methodologic approach. Additionally, viewing the findings of these studies in combination begins to establish a knowledge base about a larger proportion of the IDD population than ever before. Yet, gaps remain and there is much room for continuing to expand and improve the use of administrative claims data for research. The purpose of this study is to fill a critical gap by identifying all Medicare Fee-for-Service (FFS) adult beneficiaries with IDD, as well as IDD diagnostic subgroups, and to characterize their demographics and health outcomes. A second purpose is to draw comparisons of these variables between Medicare FFS beneficiaries with IDD and those with no disability.

Methods

Medicare and Medicaid were created in statute to provide publicly-funded health insurance to improve access to health care for people who are unlikely to have health insurance or to be underinsured. Medicare is primarily designed to provide coverage for people 65 years or older and people with disabilities of any age who are entitled to Social Security cash benefits because they are unable to work. Medicaid covers health insurance for individuals who have limited financial resources and cannot afford health insurance. Some people, referred to as 'dually eligible', qualify for and receive both Medicare and Medicaid.

Data Sources

The Centers for Medicare & Medicaid Services (CMS) compiles and stores its administrative claims data for both Medicare and Medicaid in various databases. CMS' Chronic Conditions Data Warehouse (CCW) Master Beneficiary Summary File (MBSF), the Chronic Conditions data, and the Geographic Variation Database (GVDB) beneficiary file were used for this analysis. The MBSF file was merged to all the other files using the Beneficiary Identification Number, which is the same for a single beneficiary across all CCW files. Chronic condition categories and potentially disabling conditions are based on administrative claims data and the algorithms were developed by CMS.

For this study, calendar year 2016 data was used, specifically administrative claims for Medicare FFS beneficiaries with both Medicare Parts A and B coverage during the full year. Beneficiaries who received Medicare Advantage (Medicare Part C) during any of the months in 2016 were excluded from analysis because the services they receive are collected by private companies and are not included in Medicare administrative claims data. There were 40,131,362 Medicare FFS beneficiaries, comprising 67.1% of the all Medicare beneficiaries. When including only those with Medicare Parts A and B benefits for the full year, the resulting final sample size was 30,987,261 beneficiaries.

Five disabling conditions related to IDD were selected and analyzed: autism spectrum disorder (ASD), cerebral palsy (CP), intellectual disability and related conditions (e.g., chromosomal anomalies, congenital syndromes such as Down and fetal alcohol syndromes, etc.), learning disabilities, and other developmental delays. These conditions were created based on a CMS algorithm of ICD -9 or ICD-10 codes (Detailed list available: (CMS, 2019)). The comparison group with no disabilities was comprised of adults who qualify for Medicare due to age (65 and older). Those eligible for Medicare because of a disability and/or having a diagnosis of any of the following potentially disabling conditions were excluded from the comparison group: ASD, CP, traumatic brain injury, cystic fibrosis, epilepsy, fibromyalgia (chronic pain and fatigue), deafness and hearing impairment, viral hepatitis, HIV/AIDS, intellectual disability and related conditions, learning disabilities, leukemia and lymphoma, liver disease (cirrhosis and other liver conditions), serious mental illness, migraine and other chronic headache, mobility impairment, multiple sclerosis and transverse myelitis, muscular dystrophy, other developmental delays, peripheral vascular disease, spina bifida and other congenital anomalies of the nervous system, spinal cord injury, pressure ulcers and chronic ulcers, and blindness and visual impairment.

Basic descriptive data are reported, such as number (percent). Given that the population we are describing is the whole Medicare FFS population with IDD, all differences are real differences; thus, bivariate analysis was not necessary to determine statistically significant differences. Statistical Analysis System (SAS) Enterprise Guide 7 was used for data aggregation and analytics.

Results

Among the 30,987,261 adults supported by Medicare FFS in all of 2016, the majority (74.97%) were eligible for coverage due to age, 24.68% due to having a disability or a disability with End Stage Renal Disease (ESRD), and 0.35% due to ESRD only. Also among this population, 1.56% (483,595) had at least one of the IDD related conditions for which we analyzed.

Below, we first present results describing beneficiaries with IDD supported by Medicare FFS in 2016. This includes how they qualified for Medicare, prevalence by type of IDD, demographics, and health characteristics. Next, we present results for the older adult (ages 65+) Medicare FFS beneficiaries, comparing beneficiaries with IDD to those with no disability on demographics and chronic conditions. Finally, we present findings about differences in emergency department use, and health outcomes following hospital care.

Overall Medicare FFS Beneficiaries with IDD

Within those with IDD diagnoses, the largest diagnosis group was intellectual disability and related conditions (69.9%), followed by CP (22.6%), ASD (14.4%), learning disabilities (10.7%), and other developmental delays (8.5%). The majority of beneficiaries with IDD had only one IDD diagnosis (78.0%), but 18.5% had two IDD diagnoses, and 3.0% had 3 diagnoses.

Table 1 presents the demographics for the Medicare FFS beneficiaries, by type of IDD. Overall, the greatest proportion of beneficiaries with IDD were younger than 65 years of age (77.7%), male (56.1%), non-Hispanic white (75.9%), dual eligible (qualify for both Medicare and Medicaid) (78.4%), and lived in a metropolitan area (78.7%). These characteristics varied by type of IDD. Most notably, over 90% of those with ASD were less than 65 years of age and 73.3% were male, while only 50.6% of those with learning disabilities were under age 65 and only 50.0% were male. Additionally, the majority of people with IDD and related conditions had full dual eligibility (78.4%). Those with learning disabilities were least likely (52.8%), and people with intellectual disability and related conditions most likely (85.3%) to have full dual eligibility.

Figure 1 shows the distribution of age groups for the Medicare beneficiaries with IDD compared to the general population, using data from the U.S. Census Bureau. A large percentage of Medicare FFS beneficiaries with IDD were in the 50-64 age group (33.2%) as compared to 19% of the general U.S. population. Fewer Medicare beneficiaries with IDD were in the under 30 age group (10.3%) as compared to 40.7% of the general U.S. population.

Nearly 73% of the IDD Medicare FFS beneficiaries had at least one of the chronic conditions for which we analyzed; 30.5% had three or more, and 7% had 5 or 6 chronic conditions. Prevalence for chronic conditions among beneficiaries with IDD of all ages varied by type of condition (Figure 2). Beneficiaries with IDD had high rates for all chronic conditions. Hypertension prevalence was the highest (55.8%), followed by diabetes (32.4%), chronic kidney disease (26.5%), COPD (20.6%), obesity (21.7%), chronic obstructive pulmonary disease (20.6%), and congestive heart failure (20.3%). The prevalence rate for all of these conditions were higher for the full population (all ages) of beneficiaries with IDD than those with no disability, with the exception of hypertension (results available upon request).

As shown in Figure 3, beneficiaries with IDD had very high prevalence rates for all mental health conditions. Almost 59.0% of this group had at least one of the mental health conditions we analyzed, while 17.1% had three or more mental health conditions. Prevalence for anxiety was the highest (31.5%), followed by major depressive affective disorder (28.9%), schizophrenia and other psychotic disorders (20.4%), bipolar disorder (18.4%), ADHD and other conduct disorders (14.2%), personality disorders (5.6%), and post-traumatic stress disorder (PTSD; 2.8%).

The number and proportion of Medicare FFS adults with IDD related conditions varied by state (available upon request). The size of each state's population of Medicare FFS beneficiaries with IDD related conditions ranged from a minimum of 733 in Hawaii (0.2% of all adult Medicare FFS beneficiaries with IDD related conditions) to the maximum of 41,488 in New York (8.6% of all adult Medicare FFS beneficiaries with IDD related conditions). A gross calculation using the State Health Facts Population Distribution (Kaiser Family Foundation, 2016) estimates that the mean proportion of the adult population comprised of Medicare FFS beneficiaries with IDD related conditions is 0.2%, with a range of 0.7% (Hawaii) to 0.35% (Iowa, Nebraska, North Dakota).

Younger versus Older Adult Medicare FFS Beneficiaries with IDD

Younger (under 65) Medicare FFS beneficiaries were more likely than older beneficiaries with IDD to be male (58.2% vs. 48.8%) and to have full dual status (83.0% vs. 62.3%); but, they were less likely to be white (73.8% vs. 83.1%). A larger proportion of younger Medicare FFS beneficiaries had autism (17.2 vs 4.9), intellectual disability and related conditions (72.6% vs 60.5%), but a small proportion learning disabilities (6.9% vs. 23.6%). The prevalence rates for CP and other developmental delays were more similar between the two groups (all results under this header available upon request).

Overall, the prevalence rates for chronic conditions were much lower among younger beneficiaries with IDD than the older beneficiaries with IDD. All but one of the chronic conditions prevalence rates were approximately half of those of older adults supported by Medicare FFS. The one exception was obesity, where more Medicare FFS beneficiaries with IDD under 65 (23.0%) had the diagnosis than those 65+ with IDD (17.3%).

Most mental health conditions were more prevalent among the younger group of people with IDD than the older group with IDD. These included ADHD (16.4% vs. 6.8%), bipolar disorder (19.9 vs. 13.3%), personality disorders (6.1% vs 4.0%), and PTSD (3.4% vs. 1.0%). Only depressive disorder was lower among the younger IDD beneficiaries than the older IDD beneficiaries (27.1% vs. 35.1%). The prevalence rates for anxiety and schizophrenia/psychotic disorders were similar.

Older Adult (65+) Medicare FFS Beneficiaries with IDD Compared to Those with No Disability

Table 2 presents the demographics for the older adult Medicare FFS beneficiaries, comparing beneficiaries with IDD and related conditions to those with no disability by age group. The group with IDD included 107,699 beneficiaries who were 65 years and older, and 375,896 under age 65, while the no disability group included 14,752,465 beneficiaries. Although the largest age group was 65-69 for both groups, the IDD group was proportionally younger than the no disability group overall.

Compared to those with no disability, older adults with IDD and related conditions were more likely to be male (48.8% vs. 44.1%) and to be full dual eligibles (62.3% vs. 4.6%). Race and ethnicity composition differed across these two groups, with the IDD and related conditions group comprised of more whites (83.1% vs 82.5%), blacks (10.2% vs 6.6%), and Hispanics (4.1% vs 0.4%) than the no disability group, but fewer Asian and Pacific Islanders (0.9% vs 3.0%). Geographic distribution varied little across the two groups.

Among older adult Medicare FFS beneficiaries, those with IDD and related conditions had substantially higher prevalence rates for all chronic conditions than beneficiaries with no disability (Figure 4). Hypertension prevalence was very high in both groups but nearly 15 percentage points higher among beneficiaries with IDD (84.7% vs. 70.1%). Diabetes was nearly 20 percentage points higher among the IDD group than the no disability group (47.0% vs. 27.9%). Congestive heart failure among beneficiaries with IDD (41.0%) was 2.9 times higher than for those with no disability (14.3%), and the prevalence of COPD was 2.4 times higher among the IDD and related conditions group (34.9%) compared to the no disability group (14.4%). Obesity was over 7 percentage points higher among those with IDD (17.1%) than those with no disability (10.0%).

Emergency Department Use and Health Outcomes Following Hospital Care

Table 3 displays emergency department use and health outcomes following hospital care for beneficiaries with IDD related conditions, by age group (under 65, 65+), and as compared to beneficiaries with no disabilities (65+). Outpatient emergency department visit rates were 2.3 times higher for those with IDD related conditions under 65 and almost 2.7 times higher for those with IDD related conditions 65+, compared to beneficiaries with no disabilities (38.1% vs. 43.8% vs 16.4%, respectively). Similarly, a significantly higher proportion of those with IDD related conditions from both age groups were high utilizers of emergency department visits, compared to beneficiaries with no disabilities (7.6% vs 6.5% vs. 0.5%, respectively).

Among Medicare FFS beneficiaries 65 and older, mortality within 30 days of hospitalization was nearly twice as high for those with disabilities (1.7%) compared to beneficiaries with no disabilities (0.9%); however, this rate was 22.2% lower among people with IDD under 65 years old (0.7%). Additionally, more than one out of five people with IDD related conditions under 65 and close to one out of five who were 65+ were readmitted to the hospital within 30 days of discharge, compared to less than 1 out of 10 for beneficiaries with no disabilities (Figure 5).

Discussion

Not surprisingly, the IDD Medicare FFS group had high prevalence rates for chronic conditions. In addition, they had dramatically high prevalence rates for mental health disorders. The findings for chronic conditions from this study were substantially higher than previous findings. For example, compared to our finding of 32.4% (ages 18+), Balogh et al., (2015) found a diabetes prevalence of 16.3% among Ontarian adults with IDD within a more circumscribed age group (30-69), but more general community population (identified through a registry). An estimate using 2006 Medical Expenditure Panel Survey (MEPS) data found a diabetes prevalence of 19.4% among a national sample of individuals with cognitive limitations (ages 18-65) (Reichard & Stolzle, 2011). The age range differences in these two studies account for some of the difference in prevalence, especially given that risk of diabetes increases with age. In addition, the Balogh et al.(2015), and Reichard and Stolzle (2011), studies also estimated the prevalence within broader populations. The prevalence rates for other chronic conditions found in this study among Medicare FFS adults with IDD related conditions were similarly high in comparison to those found in other studies using broader national samples (Horner-Johnson et al., 2013; Reichard et al, 2011). Our hypothesis affirms what is known about people who qualify for Medicare due any type of disability, especially those who also receive Medicaid coverage: they are more likely to have poorer health and highly complex health profiles, than those who qualify for Medicare based on age, including higher prevalence of chronic health conditions (Bynum, et al, 2017; Cubanski & Neuman, 2010; Iezzoni, 2007; Joynt et al., 2017; Ruiz et al., 2019).

A limited number of studies regarding the prevalence of mental health conditions among adults with IDD, overall, have been published. One Australian study found a prevalence of any psychiatric illness among adults with developmental disabilities of 31.7% (Morgan et al., 2008). This is much lower than our finding of 59.0% prevalence for at least one mental health disorder among the Medicare FFS population with IDD and related conditions, and Iezzoni's (2010) finding of 53.4% Medicare beneficiaries with disabilities under age 65 reporting at least one mental illness. This difference in findings between the broader IDD population and those supported by Medicare FFS is that, like it is for chronic physical conditions, Medicare eligibility criteria likely result in it covering less mentally healthy groups.

The 2016 30-day readmission rates reported for Medicare beneficiaries under 65, overall (Bailey et al., 2019), aligns closely with the same rate from this study for beneficiaries with IDD and related conditions in that age group (21.2 vs. 21.0, respectively). This rate is substantially higher than for all other types of health insurance coverage, demonstrating much room for improvements in quality of and access to care for this group. The dramatically high rate of overuse of emergency departments for routine ambulatory care is also concerning and requires further investigation into the underlying causes, especially among high utilizer.

For many people in the IDD population, chronic health conditions start at a younger age than in the general population, due to accelerated aging (Dykens, 2013; Perkins & Berkman, 2012; Ruparelia et al., 2013; Tsao et al., 2015), poorer access to health care (Krahn & Fox, 2015), limited receipt of preventive care (Havercamp & Scott, 2015), sedentary habits, poor nutrition, and obesity (Hinckenson et al., 2013; Melville et al., 2017; Rimmer et al., 2008). Less is known about the onset and prevalence of mental health conditions, to date.

Addressing high prevalence of physical and mental health conditions among beneficiaries with IDD in the Medicare FFS will require a concomitant level of public health and environmental interventions. Public health strategies may include health screenings, targeted health education, community health promotion, and evidence-based interventions for weight loss, healthy eating, and physical activity (Carmeli & Imam, 2014; Repermund & Trollor, 2015). Further, to maximize community inclusion and minimize the time required for developing these programs, we recommend using a tool such as Guidelines, Recommendations, Adaptations Including Disability (GRAIDs) (Rimmer et al., 2014) to adapt existing public health programs originally intended for the general population to include people with disabilities. Most people with IDD require supports and services across the lifespan, and most live at home with their parents as caregivers (Braddock et al., 2015); engaging caregivers in these interventions will be critical to their success. Additionally, now that people with IDD have begun to achieve longer lifespan but also have higher risk of chronic conditions, there is an urgent need for greater research to understand the unique physical and mental health care needs of aging adults with IDD.

Similar to other populations with complex health care profiles, beneficiaries with IDD supported by Medicare FFS could also benefit from evidence-based health care coordination techniques (Bowers, Owen, & Heller, 2016; Cooper et al., 2018; Reichard, Gulley, Rasch, & Chan, 2015). The CMS have acknowledged this need by awarding Health Care Innovation Awards to translate some techniques that have been effective for other populations for application with the IDD population. Although not without challenges, these programs have demonstrated promise in improving quality outcomes (Ruiz et al, 2019). Previous studies have shown similar promise on improving health appraisals and program participants' satisfaction with outcomes (Bowers, Owen, & Heller, 2016; Williamson et al. 2016). The political environment is currently ripe to support and implement these types of intervention as many states have begun participating in managed long term services and support systems (Lewis et al., 2018).

Limitations

The primary purpose of CMS administrative data is to document eligibility and code claims for reimbursement purposes rather than research. Nevertheless, use of administrative data in research offers rich information, despite the limitations of such data for this purpose. For this research, the data are restricted to only beneficiaries eligible to Medicare fee for service and therefore does not include the whole universe of the IDD population. The potentially disabling conditions in the administrative claims data are created using ICD-9 and ICD-10 codes reported in the claims. If a condition is undiagnosed, there is no other way to capture and identify the disabling condition of a beneficiary. As some services are not covered by Medicare or beneficiaries might use other types of insurance for services, some beneficiaries may not be captured and included in our IDD population. Additionally, the accuracy of coding (or coding errors) could be a limitation of administrative data.

Accurately identifying race/ethnicity is a critical element of public health surveillance. To improve the correct identification of Medicare beneficiaries who are Hispanic and Asian/Pacific Islanders, CMS uses an imputation algorithm developed by RTI International (Eicheldinger & Bonito, 2008). However, this algorithm prevents distinguishing the race (black or white) of the Hispanic population. Despite its imperfections, this algorithm has helped improve the identification of race/ethnicity among Medicare beneficiaries.

The comparison group, beneficiaries with no disabilities, excludes all Medicare beneficiaries eligible to Medicare due to disability as determined by Social Security Administration (SSA) or beneficiaries with any potentially disabling conditions as listed in the methodology. Because the SSA definition of disability includes those eligible due to mental illness, people with mental illness are excluded from the comparison group (CMS, 2019). Thus, we were not able to compare prevalence rates for mental health conditions between the IDDS group to the no disability group.

There is a need to establish a broad surveillance system to better understand and monitor the health of people with IDD. Various research methods have been used to identify, count, and better understand IDD subpopulations until a broad surveillance system can be established for the full IDD population. Most recently, researchers in the field have particularly acknowledged the value of administrative claims data for this purpose; and, several studies have confirmed the feasibility and utility of using state Medicaid claims data toward this end (Fox et al., 2015; McDermott et al., 2018; Phillips et al., 2019). Our study adds to this area of work by using diagnosis codes from Medicare administrative claims data to identify beneficiaries with IDD who were Medicare eligible for both Parts A and B for a full year. In addition, it provides the first comprehensive look at the prevalence, demographics, and health outcomes for the population, and compares these characteristics and chronic conditions among older adults with IDD to older adults with no disability supported by Medicare FFS. This study also is the first to our knowledge to present data for smaller minority populations, including Native Americans and Alaska Natives with IDD.

Conclusion

Much remains to be learned about the population of people with IDD to understand and address the health disparities they experience. Although several surveillance approaches have been published in the literature, including those using administrative claims data, none has achieved a comprehensive understanding of the size and characteristics of the full population. This study adds to what we know from other documented studies by providing prevalence, demographics, disease prevalence, emergency room use, and health outcomes following hospital care, for beneficiaries with IDD supported by Medicare FFS in one year and comparing these statistics to those of Medicare beneficiaries with no disabilities. Importantly, it demonstrates that Medicare administrative claims data can be used as a surveillance tool to better understand Medicare FFS beneficiaries with IDD. Our findings of very high prevalence across the board for very debilitating diseases also strongly highlight the urgent need for prevention, chronic disease management, and research and resources to address mental health in this highly unique population. Future studies should use Medicare administrative claims data to continue this work by taking a more fine-grained look at chronic conditions and mental health disorders among the IDD subgroups, as well as examining health trends over time using longitudinal data, and make further comparisons to other Medicare populations, to inform policy, practice, and fiscal planning.

Currently, the CMS Office of Minority Health (OMH) is in the process of further refining the ICD-9 and ICD-10 codes used to identify each of the specific disabling conditions, by collecting feedback from clinicians, researchers, and experts in the field. Once refined, larger categories of disabilities such as IDD will be created and validated, comparing CMS administrative claims data to survey data. Finally, CMS OMH will use these new groupings to examine the population’s utilization of health care such as hospitalizations, emergency department visits, hospital readmissions, and mortality.

In addition, the Administration on Community Living and CMS are collaborating to determine the specific questions to include in the Medicare Current Beneficiary Survey (MCBS) to identify Medicare FFS IDD beneficiaries. This will also allow for surveillance of a sample of Medicare FFS beneficiaries with IDD by allowing for and examination of such outcomes as access to health care, usual source of care, barriers to care, and use of preventive services.

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Table 1. Demographics of Medicare FFS by IDD Related Conditions, CY2016

	Autism Spectrum Disorders	**Cerebral Palsy**	**Intellectual Disabilities and Related Conditions**	**Learning Disabilities**	**Other Developmental Delays**	**Beneficiaries with IDD***
Total (N)	**69,844**	**109,320**	**338,005**	**51,551**	**41,025**	**483,595**
OREC						
Aged	1,614 (2.31%)	5,564 (5.09%)	12,167 (3.6%)	18944 (36.75%)	2,054 (5.01%)	38,019 (7.86%)
Disabled	68,007 (97.37%)	103,379 (94.57%)	323,160 (95.61%)	32155 (62.38%)	38,511 (93.87%)	441,959 (91.39%)
ESRD only	133 (0.19%)	189 (0.17%)	1,251 (0.37%)	260 (0.5%)	292 (0.71%)	1,774 (0.37%)
Disabled with ESRD	90 (0.13%)	188 (0.17%)	1,427 (0.42%)	192 (0.37%)	168 (0.41%)	1,843 (0.38%)
Age Group						
<65	64,526 (92.39%)	86,885 (79.48%)	272,857 (80.73%)	26084 (50.6%)	32,669 (79.63%)	375,896 (77.73%)
65-74	4,103 (5.87%)	15,803 (14.46%)	46,211 (13.67%)	10152 (19.69%)	5,825 (14.2%)	67,584 (13.98%)
75+	1,215 (1.74%)	6,632 (6.07%)	18,937 (5.6%)	15315 (29.71%)	2,531 (6.17%)	40,115 (8.3%)
Sex						
Male	51,498 (73.73%)	57,265 (52.38%)	188,555 (55.78%)	25765 (49.98%)	22455 (54.73%)	271,385 (56.12%)
Female	18,346 (26.27%)	52,055 (47.62%)	149,450 (44.22%)	25786 (50.02%)	18570 (45.27%)	212,210 (43.88%)
Race / Ethnicity						
White	53,288 (76.3%)	84,158 (76.98%)	254,647 (75.34%)	39414 (76.46%)	30,846 (75.19%)	366,852 (75.86%)
Black	9,074 (12.99%)	13,995 (12.8%)	49,375 (14.61%)	6812 (13.21%)	5,181 (12.63%)	67,438 (13.95%)
Hispanic	4,062 (5.82%)	7,553 (6.91%)	23,128 (6.84%)	3468 (6.73%)	3,205 (7.81%)	32,109 (6.64%)
Asian and Pacific Islander	1,311 (1.88%)	1,438 (1.32%)	4,293 (1.27%)	812 (1.58%)	707 (1.72%)	6,660 (1.38%)
American Indian and Alaska Native	417 (0.60%)	891 (0.82%)	2,661 (0.79%)	367 (0.71%)	524 (1.28%)	3,869 (0.8%)
Dual Status						
No Dual Status	9,345 (13.38%)	17,999 (16.46%)	34,245 (10.13%)	20,608 (39.98%)	5,352 (13.05%)	80,069 (16.56%)
Partial Dual Status	3,627 (5.19%)	4,840 (4.43%)	15,445 (4.57%)	3,703 (7.18%)	2,569 (6.26%)	24,620 (5.09%)
Fully Dual Status	56,872 (81.43%)	86,481 (79.11%)	288,315 (85.3%)	27,240 (52.84%)	33,104 (80.69%)	378,906 (78.35%)
Geography						
Metropolitan	58,166 (83.28%)	87,056 (79.64%)	264,555 (78.27%)	41,484 (80.48%)	33,173 (80.87%)	380,424 (78.67%)
Micropolitan	7,498 (10.74%)	13,689 (12.52%)	45,800 (13.55%)	6,050 (11.74%)	5,043 (12.29%)	63,620 (13.16%)
Non-CBSA	4,178 (5.98%)	8,570 (7.84%)	27,636 (8.18%)	4,012 (7.78%)	2,806 (6.84%)	39,524 (8.17%)

OREC = Original Reason for Entitlement, or the original reason a beneficiary was eligible for Medicare

Dual Status = Whether beneficiaries were eligible for both Medicare and Medicaid

*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

** Beneficiaries were excluded if they were eligible to Medicare because of a disability and / or had any potentially disabling conditions.

Note: Numbers may not add up to the total due to some beneficiaries missing some data

Table 2. Demographics of Medicare FFS Beneficiaries Stratified by Age, 65+ and <65, CY2016

	65+ Medicare FFS Beneficiaries		**<65 Medicare FFS Beneficiaries**
	Beneficiaries with IDD Related Conditions*	**Beneficiaries with no Disabilities****	**Beneficiaries with IDD Related Conditions***
Total (N)	**107,699**	**14,752,465**	**375,896**
Age Group			
<30	-	-	49,826 (13.26%)
30-39	-	-	76,442 (23.69%)
40-49	-	-	89,033 (23.69%)
>= 50 - <65	-	-	160,595 (42.72%)
65-69	39,658 (36.82%)	4,209,477 (28.53%)	-
70-74	27,926 (25.93%)	3,965,564 (26.88%)	-
75-79	17,221 (15.99%)	2,780,231 (18.85%)	-
80+	22,894 (21.26%)	3,797,193 (25.74%)	-
Sex			
Male	52,498 (48.75%)	6,509,535 (44.13%)	218,887 (58.23%)
Female	55,201 (51.25%)	8,242,928 (55.87%)	157,009 (41.77%)
Race / Ethnicity			
White	89,528 (83.13%)	12,166,161 (82.47%)	277,324 (73.78%)
Black	11,011 (10.22%)	965,642 (6.55%)	56,427 (15.01%)
Hispanic	4,469 (4.15%)	758,192 (0.40%)	27,640 (7.35%)
Asian and Pacific Islander	921 (0.86%)	441,670 (2.99%)	5,739 (1.53%)
American Indian and Alaska Native	427 (0.40%)	58,899 (0.40%)	3,442 (0.92%)
Dual Status			
No Dual Status	35,410 (32.88%)	13,949,531 (94.56%)	44,659 (11.88%)
Partial Dual Status	5,182 (4.81%)	124,891 (0.85%)	19,438 (5.17%)
Fully Dual Status	67,107 (62.31%)	678,043 (4.60%)	311,799 (82.95%)
Geography			
Metropolitan	83,359 (77.41%)	11,524,506 (78.30%)	297,065 (79.03%)
Micropolitan	14,437 (13.41%)	1,782,666 (12.11%)	49,183 (13.08%)
Non-CBSA	9,895 (9.19%)	1,411,069 (9.59%)	29,629 (7.88%)

*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

** Beneficiaries were excluded if they were eligible to Medicare because of a disability and / or had any potentially disabling conditions.

*** Dual Status = Whether beneficiaries were eligible for both Medicare and Medicaid

Note: Numbers may not add up to the total due to some beneficiaries missing some data

Table 3. Number and Percent of Health Outcomes for Beneficiaries IDD Related Conditions, by Age Group, CY2016

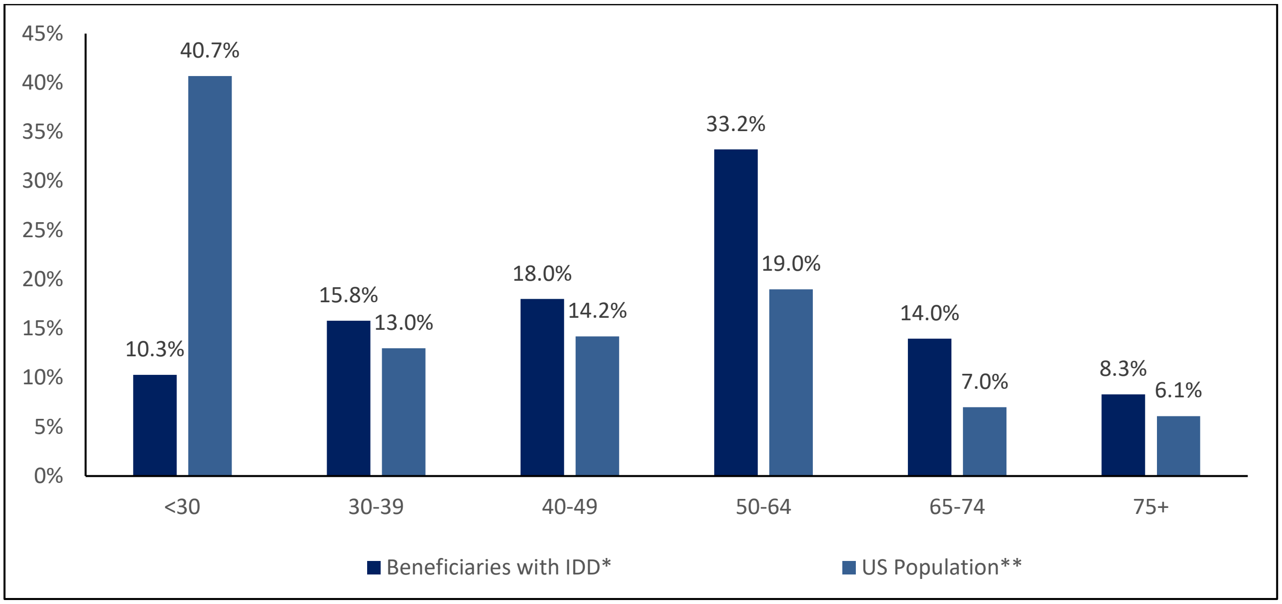
	IDD Related Conditions* Under 65	**IDD* 65+**	**No Disabilities****
Mortality within 30-days of Hospitalization	823 (0.7%)	1,158 (1.7%)	12,565 (0.9%)
Outpatient Emergency Department Visits	143,012 (38.1%)	47,170 (43.8%)	2,422,299 (16.4%)
High Utilizer* Outpatient Emergency Department Visits	28,384 (7.6%)	7,000 (6.5%)	77,960 (0.5%)

*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

** Beneficiaries were excluded if they were eligible to Medicare because of a disability and / or had any potentially disabling conditions.

***High Utilizer is defined as having >= 4 Emergency Visits in a 12 month period

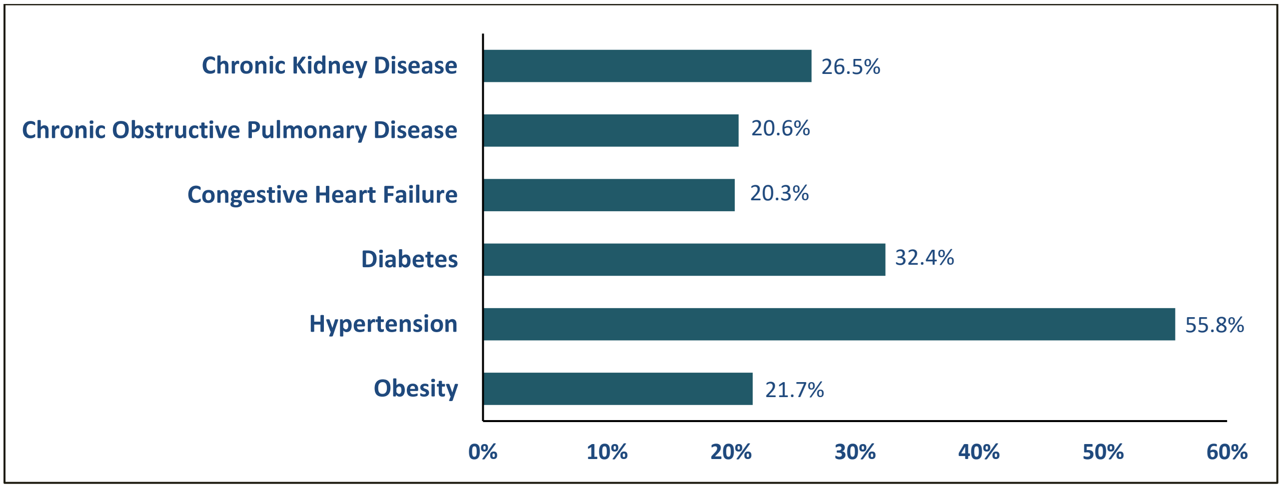
Figure 1. Distribution of Medicare FFS Beneficiaries with IDD (CY2016) Compared to the Total U.S. Population (CY2010), by Age Group



*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

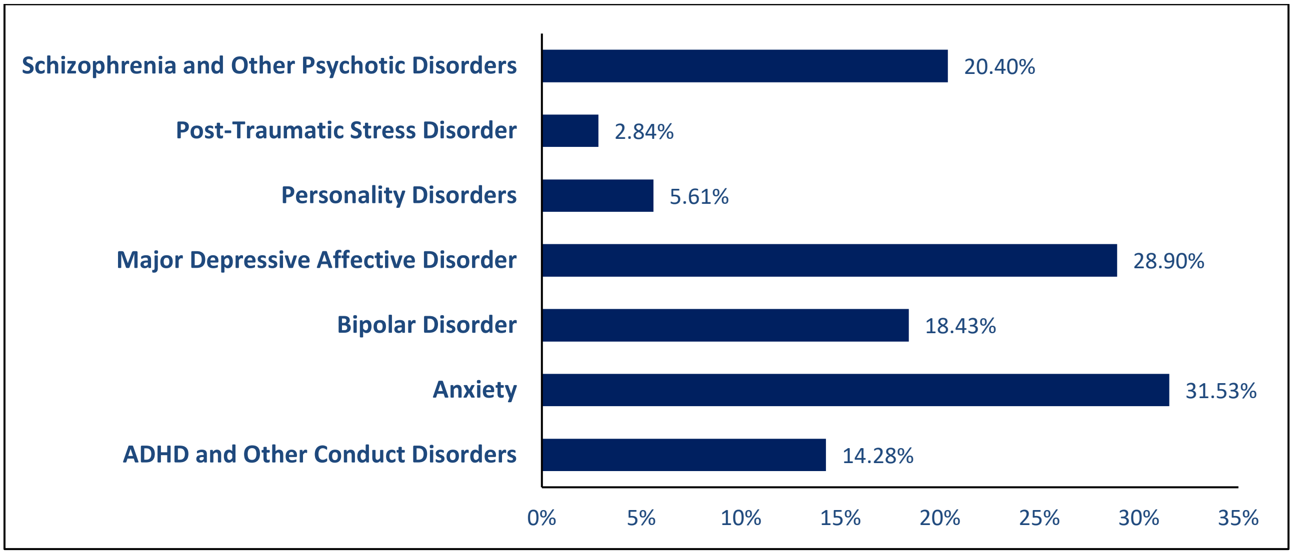
** US Population age group totals. U.S. Census Bureau: American Fact Finder website, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_SF1_QTP1&prodType=table

Figure 2. Prevalence of Chronic Conditions for All Medicare FFS Beneficiaries with IDD, CY2016



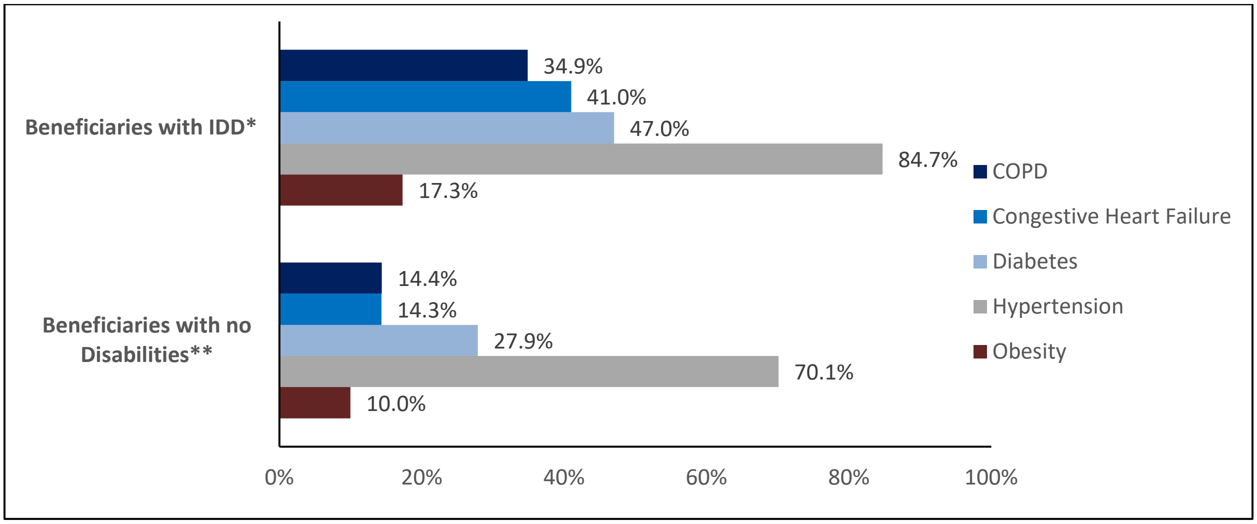
*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

Figure 3. Prevalence of Mental Health Disorders for All Medicare FFS Beneficiaries with IDD, CY2016



*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

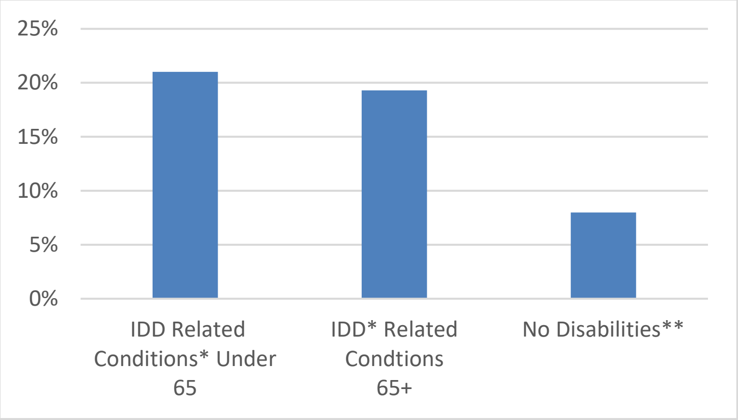
Figure 4. Chronic Condition Prevalence Among Older Adult Medicare FFS Beneficiaries, Comparing IDD to No Disability, CY2016



*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

** Beneficiaries were excluded if they were eligible to Medicare because of a disability and / or had any potentially disabling conditions.

Figure 5. Unplanned 30 Day Hospital Readmission Rates



*A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

** Beneficiaries were excluded if they were eligible to Medicare because of a disability and / or had any potentially disabling conditions.