

# What We Can Learn about Individuals with IDD from Medicaid Claims Data



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## Introduction

- Despite the evidence that many people with intellectual and developmental disabilities (IDD) have substantial and complex health care needs, little research has been conducted to better understand the health care utilization and disease prevalence rates unique to this population. Further, among the work that has been conducted (1-6), almost none of it has compared health outcomes for people with IDD to those of other disability subgroups.
- This type of work is important for public health surveillance to better meet the needs of this population (7-13), and it is especially important as public health insurance programs create and change policies in response to economic pressures such as CMS initiatives to improve care coordination for dually eligible (14-16).
- For this presentation we compare and contrast the findings of demographic characteristics, comorbid medical conditions, and overall patterns of health care utilization and expenditures found between those with IDD and those in other disability groups.

## Among those with IDD:

- The majority of Medicaid costs were not for medical care, but for Home and Community Based Services (HCBS) (64.1%) or long term care (19.5%).
- Greater than 94% used outpatient care while 18.9% used inpatient care.

## Methods

- We used eligibility data and paid claims (including Medicare cross-over claims) from the Kansas Department of Health and Environment, Division of Health Care Finance for all adults enrolled in the Kansas Medicaid, fee-for-service Aged, Blind, and Disabled (ABD) program from July 2005 (FY2006) through June 2009 (FY2009).
- As no single eligibility variable clearly identifies the qualifying disability of persons enrolled in the Kansas Medicaid ABD program, we combined eligibility codes and claims-based diagnoses to create four mutually exclusive cohorts including: Intellectual or Developmental Delay (IDD), Severe Mental Illness (SMI), Physical Disability (PD), Aged. All remaining individuals were classified as Other.
- For information on the algorithm used to create and define the cohorts, see *Learning your ABDs: Variation in health care utilization across Kansas Medicaid disability groups* (Shireman, Reichard & Hunt, in press).
- We used a comorbidity classification system designed specifically with/for Medicaid data: the Chronic Illness and Disability Payment System or CDPS (17).
- We computed summary measures for each type of service at the person level: total health expenditures, percent of expenditures, percent using service, and expenditures per person using service. Total health care expenditures reflected Kansas Medicaid's expenditures only. We present major categories of expenditures by year and type of disability.
- Since outpatient and professional services incorporate medical care and supportive services, we provide more detail for distinguishing between those categories, separating out HCBS, home health, and transportation costs.

## Results

- In FY 2009, adults with IDD comprised 15.6% (15,815) of the adult Kansas Medicaid population. They had a mean age of 44 years, with only 17.5% over 60 years old. Half of them were female, and the majority lived in medically underserved areas (70.7%), and were dually eligible for both Medicaid and Medicare (61.5%). Racial proportions were roughly representative of the State of Kansas (86.7% white, 10.3% black, 2.9% other) (Table 1).

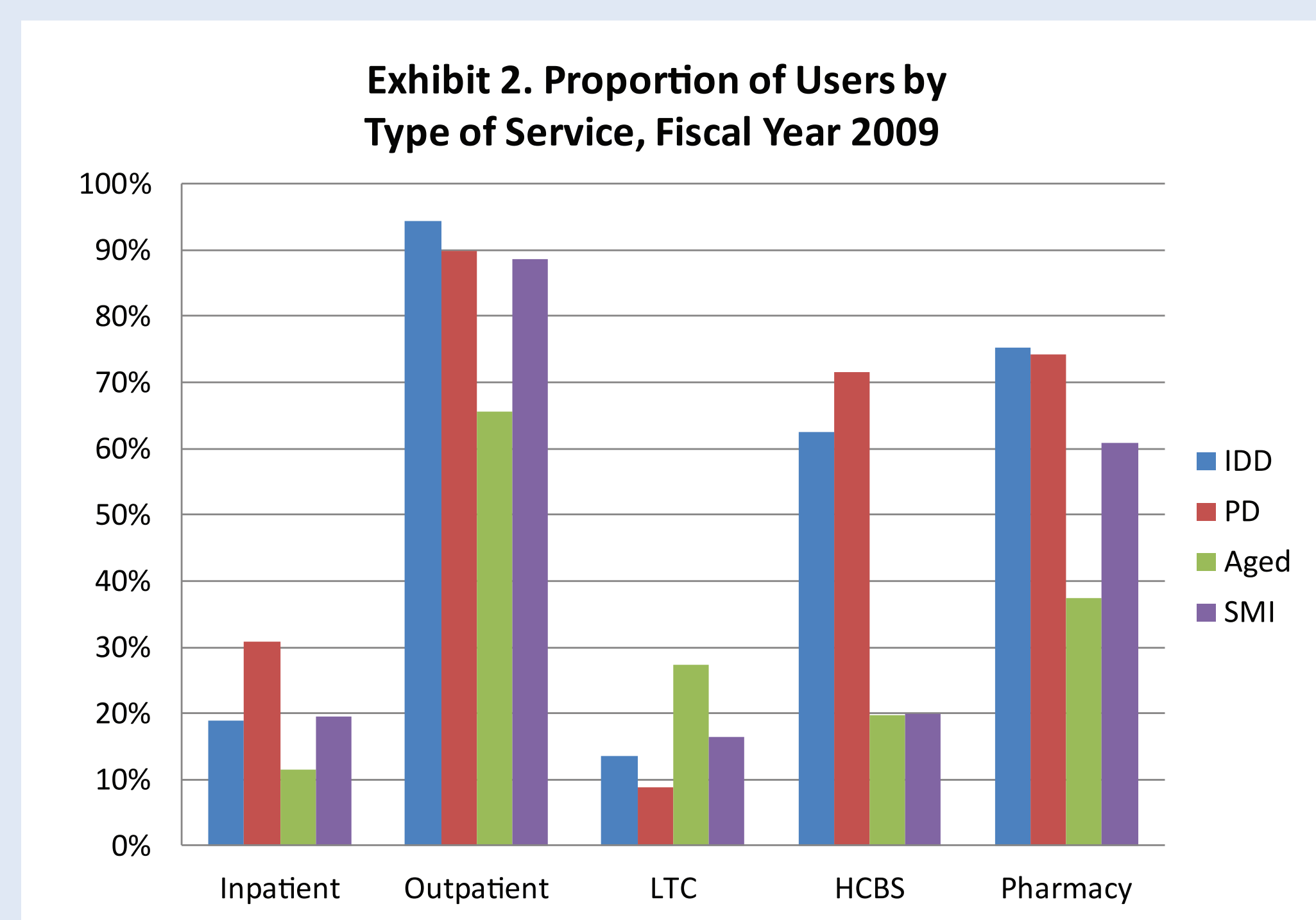
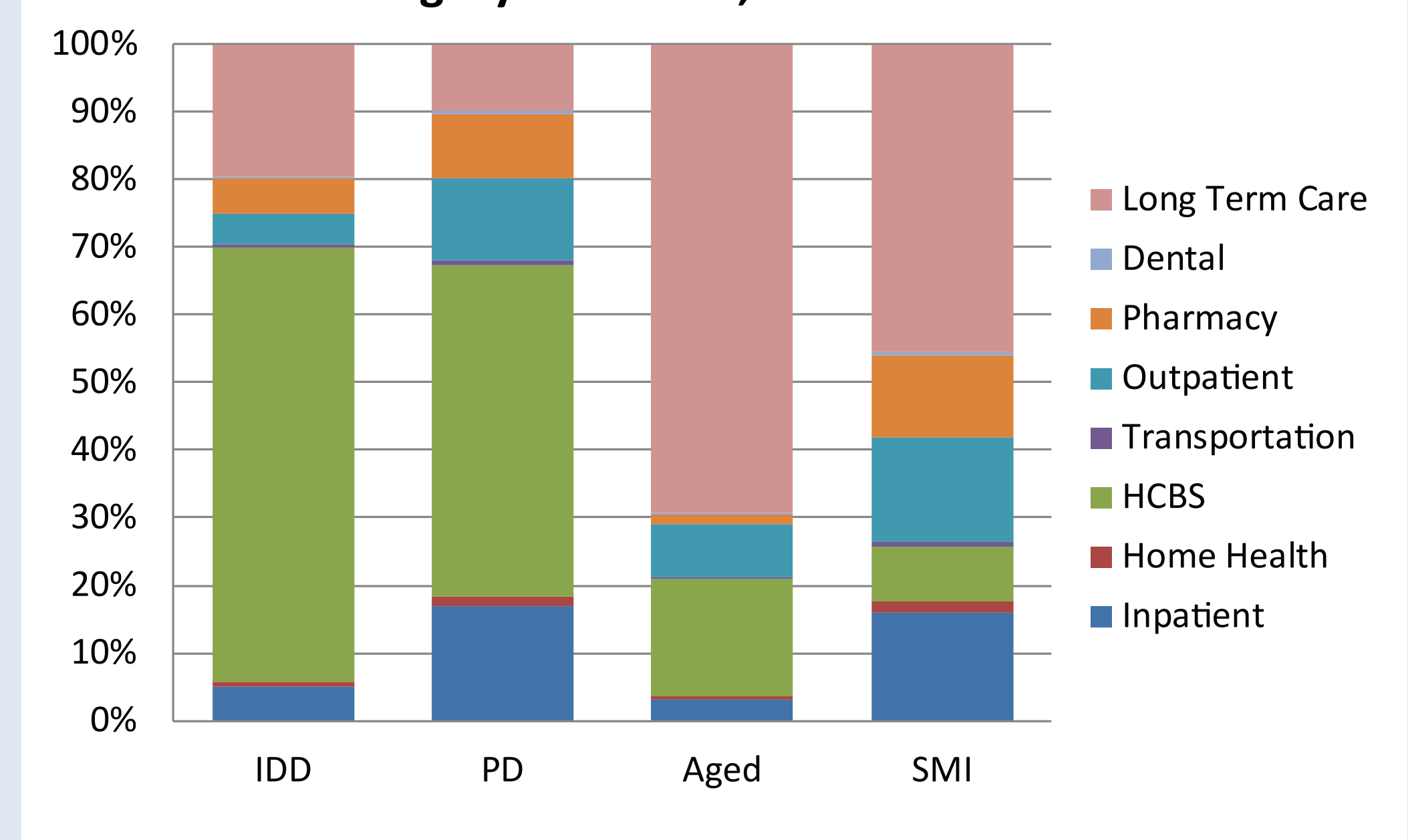
Table 1. Demographic characteristics of Kansas Medicaid aged, blind and disabled (ABD) enrollees, fiscal year 2009

	IDD*	PD*	Aged	SMI*	Other
Number of persons	15,815	10,873	25,329	32,385	17,062
Percent of ABD population	15.6	10.7	25.0	31.9	16.8
Age, mean (SD) years	43.9 (16.8)	52.5 (11.7)	77.0 (12.0)	53.5 (19.3)	47.9 (12.4)
Age distribution (%):					
18-29 yrs	25.2	4.6	1.0	11.7	12.0
30-39 yrs	16.6	8.4	0.8	11.8	10.8
40-49 yrs	21.7	22.9	1.4	21.2	22.8
50-59 yrs	18.8	35.4	1.0	22.3	36.1
60-69 yrs	9.9	24.9	18.6	11.0	18.3
70-79 yrs	4.7	2.6	34.5	8.6	0.0
80 yrs plus	2.9	1.3	42.7	13.3	0.0
Gender (%):					
Female	50.0	64.1	68.8	61.4	45.6
Male	50.0	35.9	31.2	38.6	54.4
Race (%):					
White	86.7	78.8	82.4	83.0	76.0
Black	10.3	17.9	9.1	12.7	18.9
Other	2.9	3.3	8.5	4.3	5.0
Dual Eligibility (Medicare-Medicaid)	61.5	60.9	81.3	58.6	41.6

\*IDD, intellectual or development delay; PD, physical disability; SMI, severe mental illness

- Despite their younger age, the IDD cohort carried substantial disease burden. The most common problems were related to nervous system (98.2%), pulmonary (81.0%), skeletal/connective tissue (79.3%), metabolic (77.8%), skin (76.6%), gastrointestinal (72.9%) and psychiatric (72.1%) concerns. These rates were higher than those of the Aged group, but lower than those of the PD group.
- In FY 2009, the IDD cohort incurred the highest mean cost among all groups, of \$32,408, with \$512.5 million in total Medicaid expenditures for all covered services (Table 2); it is important to note, however, that the majority of these costs were for Home and Community Based Services (HCBS) (64.1%) or long term care (19.5%), not medical care (Exhibit 1). These were followed by pharmacy (5.2%), inpatient (5.1%), outpatient (4.7%) and home health (0.8%) services. These categories of service constituted substantially different proportions from other subgroups.

Exhibit 1. Proportion of Total Expenditures for Category of Service, FY2009



- Nearly all people with IDD (94.4%) used outpatient care which was the highest portion of users of this type of service among all groups, with a mean cost of \$1,601 per user. Over 72% of the IDD cohort who used outpatient care had at least one primary care visit in FY2009. The mean number of outpatient visits overall was 43.2, while the mean number of primary health care visits was 4.1.
- Alternatively, a smaller proportion of the IDD group (18.9%) used inpatient care than the PD (30.9%) and SMI (19.6%) groups. Mean annual cost per hospital user for persons with IDD was among the lowest at \$8,651 with an average of 1.9 visits per user in FY2009. The top ten most common reasons for hospitalization in this group included pulmonary (COPD, pneumonia, bronchitis), psychiatric, bacterial infection (septicemia, cellulitis), gastrointestinal, rehabilitation, kidney and urinary tract infection, seizures, joint replacement, and diabetes.
- A majority (75.3%) of the IDD group used prescription medication, a greater proportion than any of the other groups. The average cost per person for pharmacy was \$2,256, with a mean of 8.4 prescriptions per person, overall, in FY2009.

- HCBS care was used by 62.6% of the IDD cohort, second only to the PD group (71.5%), with a mean cost of \$33,180 per user, which was 2-10 times more than any other group.

- Almost 30% of the IDD group used transportation services with an average cost of \$395, second only to the PD group (33.8%) with an average cost of \$566 per person.

## Discussion

- The majority of adults with IDD enrolled in Medicaid were younger, Caucasian, and have different prevalence and ordering of major mental health and medical comorbidities from other disability subgroups.
- Adults with IDD incurred the highest annual costs within Kansas Medicaid, driven by HCBS services followed by long-term care. Clearly, Medicaid provides mostly long-term custodial care for persons with IDD through its HCBS and nursing facility coverage, with comparatively low associated medical costs, similar to findings of others (14).
- The chronic disease prevalence rates for adults with IDD in this study were higher overall than findings published by others (18-22), largely because of differing methodologies. However, their most prevalent set of comorbidities stemmed from central nervous system conditions and symptoms, though for their age, they carried a heavy disease burden including both medical and mental health conditions. Notably, only 20.5% were flagged as having diabetes despite the high rate of obesity in this population (23, 24).
- The study sample of those with IDD had a greater proportion (72.4%) and mean number of primary care visits (4.1) than those reported by Hall (1) (60.5%; 1.09). Similarly, a greater proportion

of the study sample of people with IDD used inpatient care (18.9%) than general population (11.7%) according to the US Census Bureau (2012). These results are not surprising given the high disease prevalence rates.

## Conclusions

- In summary, our study contributes to the existing knowledge about health care utilization and comorbidity of people with IDD supported by Medicaid, and compares this population to other disability groups supported by Medicaid. Although the IDD group experiences substantial rates of disease, the costs associated with their use of medical resources was low. The large majority of their costs stems from HCBS and long term care services. Additionally, while most people used outpatient care, only a small proportion of those with IDD required inpatient care. These results provide evidence that is relevant and useful for the state Medicaid program in its decision-making for policy and practice.

Table 2. Major sources of health care utilization and expenditures by disability subgroup, fiscal year 2009

	Measure	Inpatient	Outpatient	LTC	HCBS	Pharmacy	Transport	Home Health
IDD*	Expenditures (% total)	5.1%	4.7%	19.5%	64.1%	5.2%	0.4%	0.8%
	Service users (% using)	18.9%	94.4%	13.6%	62.6%	75.3%	28.9%	4.6%
	Cost/user (mean)	\$8,651	\$1,601	\$46,223	\$33,180	\$2,256	\$395	\$5,381
PD*	Expenditures (% total)	16.9%	12.1%	9.9%	48.9%	9.5%	0.9%	1.3%
	Service users (% using)	30.9%	89.9%	8.9%	71.5%	74.2%	33.8%	9.4%
	Cost/user (mean)	\$12,211	\$3,010	\$24,764	\$15,253	\$2,858	\$566	\$3,188
Aged	Expenditures (% total)	3.1%	7.9%	69.1%	17.4%	1.3%	0.2%	0.5%
	Service users (% using)	11.6%	65.6%	27.4%	19.7%	37.5%	11.2%	1.7%
	Cost/user (mean)	\$2,688	\$1,214	\$25,440	\$8,909	\$342	\$158	\$3,010
SMI*	Expenditures (% total)	16.0%	15.4%	45.3%	8.1%	12.1%	0.6%	1.5%
	Service users (% using)	19.6%	88.7%	16.4%	20.0%	60.8%	20.1%	3.5%
	Cost/user (mean)	\$7,932	\$1,690	\$26,972	\$3,980	\$1,943	\$313	\$4,130
Other	Expenditures (% total)	34.4%	30.9%	19.4%	0.8%	12.5%	0.7%	0.4%
	Service users (% using)	9.3%	60.8%	1.7%	3.6%	36.2%	6.4%	1.1%
	Cost/user (mean)	\$13,089	\$2,008	\$46,482	\$1,413	\$1,396	\$384	\$1,272

\*IDD, intellectual or development delay; PD, physical disability; SMI, severe mental illness

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- This work was funded, in part, under a Research and Training Center grant from the National Institute on Disability and Rehabilitation Research, award number H133B060018.
- The data for this project were provided by the Division of Health Care Finance in the Kansas Department of Health and Environment (KDHE) through a Business Associates Agreement with the University of Kansas Medical Center Research Institute. The conclusions and opinions do not necessarily reflect the opinion or policies of KDHE or the Centers for Medicare & Medicaid Services (CMS).