



# Evaluation of Health Care Disparities for Individuals with Intellectual and Developmental Disabilities in Ohio

Maryse R. Amin<sup>1</sup> · Julie P. Gentile<sup>2</sup> · Barbara Edwards<sup>3</sup> · Mark Davis<sup>4</sup>

Received: 25 June 2019 / Accepted: 19 June 2020 / Published online: 26 June 2020  
© Springer Science+Business Media, LLC, part of Springer Nature 2020

## Abstract

The purpose of the study was to determine the acute and long term services and supports (LTSS) utilization, cost of health care and disparities in access of care for individuals with Intellectual and Developmental Disabilities (IDD). Individuals with IDD on a waiver (receiving Medicaid-funded LTSS in community settings) compared to non-IDD individuals on a waiver control group were compared using Ohio Medicaid claims data from calendar year 2013. Results found the IDD Waiver population had lower utilization rates for emergency department visits, hospital admissions, and hospital readmissions within 30 days compared to the Non-IDD Waiver population and lower PMPM expenditures across all medical service categories except pharmacy. However, the IDD Waiver population possessed greater PMPM costs for LTSS and therefore greater overall costs of care. Furthermore, 94% of IDD Waiver individuals had an episode of care for neurological conditions, with the second most frequent episode of care being for mental health services. The two most frequent episodes of care for individuals in the Non-IDD Waiver group were for conditions related to treatment (medical/surgical) and musculoskeletal conditions. The goal of this research was to investigate the health care needs of individuals with IDD that may vary from other long term care populations. The differences in health care needs for individuals with IDD require health systems and care management that is tailored to the sub-population, with an emphasis on treatment for neurological and mental health conditions. The typical focus of care management efforts on reducing unnecessary utilization of hospital services may be less relevant to the IDD Waiver population. The results of this study will be used to make recommendations regarding the unique health care needs of individuals with IDD.

**Keywords** Intellectual and developmental disabilities · IDD · Medicaid · Long term services and supports · LTSS · Care management

---

Barbara Edwards: Retried.

---

✉ Julie P. Gentile  
Julie.gentile@wright.edu

Maryse R. Amin  
Aminmr@mail.uc.edu

<sup>1</sup> Center for Epidemiological Research for Individuals With Intellectual and Developmental Disabilities (CERIIDD), 1152 Goodale Blvd, Columbus, OH 43212, USA

<sup>2</sup> Ohio's Coordinating Center for Excellence in Mental Illness/Intellectual Disability, Department of Psychiatry, Wright State University, 627 Edwin C. Moses Blvd, Dayton, OH 45417, USA

<sup>3</sup> Health Management Associates, Columbus, OH, USA

<sup>4</sup> Pennsylvania Advocacy and Resources for Autism and Intellectual Disabilities, Lemoyne, PA, USA

## Background

The lack of widespread epidemiological and actuarial knowledge regarding individuals with intellectual and developmental disabilities (IDD) may contribute to poorer health outcomes and inadequate access to health care services (Potvin et al. 2019; Grier et al. 2018). Individuals with IDD represent approximately 1–3% of the population, with an upsurge in population due to increased life expectancy (CDC 2017; Bauer et al. 2019). Many challenges are observed among adults with IDD, including disproportionately higher rates of preventable mortality, co-morbidities and chronic medical and psychiatric conditions. Individuals with IDD show a gap in overall health status; this patient population has a higher prevalence of medical conditions in virtually every organ system and have often limited expressive language skills, resulting in less subjective data available for the

physician (Brameld et al 2018). There is a high prevalence of behavioral presentations, more poly-pharmacy, and many physicians are not trained to treat patients with IDD, so may be less likely to perform a thorough physical examination. In addition, individuals with IDD can have poorer health outcomes when hospitalized than those without IDD. They are at greater risk of being hospitalized in the Intensive Care Unit and experience complications during hospitalization (Ailey et al. 2014).

Certain chronic conditions and co-morbidities that are frequently found among individuals with IDD can drive the healthcare costs for this population. A study examining the most common hospital discharge codes for the Medicare-covered IDD population, based on Medicare Severity Diagnosis Related Groups (MS-DRGs), found psychoses (16.9%), seizure disorders (7.9%), septicemia (5.4%), respiratory infections (3.1%) and pneumonia (2.8%) to be the top five most frequent MS-DRGs (Ailey et al. 2014). These common conditions accounted for 36% of Medicare reimbursed hospitalizations for individuals with IDD. These common and debilitating conditions for individuals with IDD vary with regard to illness presentation, course of illness, and outcomes compared to the general population. A study conducted in 2012 found that out of 1,000 patients studied, two thirds of IDD patients had co-morbidities. Furthermore, 40% had four or more chronic conditions (Hsieh et al. 2012). In a study comparing the mortality rate of individuals with moderate to severe IDD to the general population, a three-fold increase in mortality for those with moderate to profound IDD (Hosking et al. 2016) was observed. Mortality was particularly high in young adults, women living in the city and individuals with Down syndrome.

The purpose of this study was to examine expenditures on healthcare services for individuals with IDD in Ohio by analyzing Medicaid claims data. The goal of the study is to support improved quality of life, better medical outcomes, and more cost-effective utilization and coordination among the delivery care systems by defining and clarifying the unique healthcare needs of individuals with IDD. The results of this study will enable us to make recommendations for the coordination and provision of health care services to the IDD population in Ohio and nationally.

## Method

### Subjects and Data

Using a data base representing total Ohio Medicaid claims expenditures for 385,345 individuals covered under the Aged, Blind and Disabled eligibility categories, a study group and a control group were identified. Individuals were aggregated into eight mutually exclusive groups based on the

underlying presence or absence of developmental disabilities and the type of Medicaid services received, including whether the individual received care in institutional settings (i.e., a nursing facility or an intermediate care facility for individuals with intellectual disability (ICF/IID)) or in community based settings. From the eight categories, Individuals Receiving IDD Waiver Services (community LTSS, an aggregation of four separate IDD-related waiver programs) ( $n = 34,599$ ) were selected for evaluation in comparison to a control group of Individuals Receiving Non-IDD-Based Waiver Services ( $n = 60,182$ ). Both the study group and the control group are composed of individuals who have been assessed as having an institutional level of care need and who are receiving community-based LTSS in addition to primary and acute care services. The fiscal year of the study was based on Medicaid coverage between January 2013 and December 2013. Medicaid claims data were obtained from the Ohio Department of Medicaid.

Medicaid Waivers provide an alternative to institutional services to people who would otherwise need to live in an ICF/IID or a nursing home. Waivers offer services like personal care, homemaker services, respite care, and other LTSS designed to enable individuals to live in home and community-based settings. The design of available waiver services (including amount, duration and scope) varies across waiver programs offered by the state. The Medicaid primary and acute care benefit design, including pharmacy, is identical across waiver programs.

### Eligibility Criteria

Eligibility criteria was based on individuals with an IDD clinical ICD-10 diagnosis receiving Medicaid benefits (Non-Duals) or individuals with a similar diagnosis receiving both Medicaid and Medicare benefits (Dually eligible) with at least one episode of care within one fiscal year.

### Analyses

Data for the study and control groups were stratified by 29 episodes of care summary groups, age (child  $\leq 18$  years vs. adult  $\geq 19$  years), county (88) in Ohio where care was received, health care/LTSS provider specialty (58 specialties), type of care (Emergency Department (ED), Hospital, Outpatient, Dental, and Pharmacy), and cost of care (total and by type).

Episodes of care represented 191 unique occurrences grouped into 29 classifications by major disease categories. Episodes of care were defined by the diagnosis codes present on claims data to relate multiple claims for a condition into a single care episode. Preventive care services were defined as a well child or adult visit, any type of diagnostic screening

or immunization. Descriptive statistics of demographic characteristics was calculated.

Medicaid expenditures were calculated based on a per member per month (PMPM) basis. Sample sizes in each group vary based on categories in which Medicaid recipients are placed. Patient confidentiality met requirements of Health Insurance Portability and Accountability Act (HIPAA) of 1996 and all business associate agreements. Unpaired t tests were conducted to determine statistical significance between the IDD waiver study group and Non-IDD wavier groups.

### Categorizing Expenditures

With guidance from medical experts, episodes of care for each diagnosis was assigned to 1 of 29 categories. Specifically, common chronic conditions were kept as individual categories, including asthma, breast cancer, colon cancer, diabetes, HIV infection, hypertension, immunodeficiency disorders, lung cancer, obesity and prostate cancer. These episodes of care were kept separate to be able to evaluate which common chronic conditions components were of greatest concern. Other Medicaid expenditures were aggregated into 9 categories: dental services, emergency department, inpatient admissions, waiver, long term care, medical services, Medicare (i.e., Medicaid paid Part B premiums), outpatient services and pharmacy.

### Results

Table 1 shows the study group and comparison group by age. The IDD Waiver group had a higher percentage of children (14.5%) compared to the Non-IDD Waiver group (1.4%). This likely reflects the fact that most disabilities with onset in childhood are generally classified as being an IDD.

Table 2 shows the top ten episodes of care for the IDD Waiver population. The most frequent episodes of care for the IDD Waiver population were neurological (94.1%) and mental health (52.8%), followed by musculoskeletal (34.8%, otolaryngology (27.1%) and ophthalmology

**Table 1** Total count of target population and comparison group by age distribution

Grouping	< 18 years (%)	> 19 years	Total members
IDD Waiver	5036 (14.5%)	30,000 (86.7%)	34,599
Non-IDD Waiver	862 (1.4%)	59,346 (98.6%)	60,182

Sum of age group totals may not equal total if recipients turned nineteen part way through report period and had an event when eighteen and again when nineteen

IDD Intellectual and developmental disability

**Table 2** Top ten episodes of care for the IDD Waiver population by age categories, January–December 2013

Episode of care	IDD Waiver (study group)			
	< 18 years	> 19 years	Total	% of Total
Neurological	4885	27,711	32,554	94.1
Mental health	3327	14,964	18,281	52.8
Musculoskeletal	1303	10,756	12,044	34.8
Otolaryngology	1684	7719	9385	27.1
Ophthalmology	1023	7025	8045	23.3
Dermatologic disorders	677	7287	7957	23
Gastrointestinal	929	6000	6914	20
Pulmonary	764	4583	5338	15.4
Immunology/allergy	271	6340	6610	19.1
Nephrology/renal	347	4108	4108	11.9

Sum of age group totals may not equal total if recipients turned nineteen part way through report period and had an event when eighteen and again when nineteen

IDD Intellectual and developmental disability, IDD Waiver groups—IO individual options (IO) Waiver, Level 1, Self Waiver and transition Waiver

(23.3%). The common chronic conditions determined for the general population, such as heart disease, cancer, and chronic lung disease (CDC 2019), were not among the top ten episodes for the IDD Waiver population. For the Non-IDD Waiver group, condition related to treatment (medical/surgical) (71.7%) and musculoskeletal (55.8%) episodes were the most frequent. Followed by hypertension

**Table 3** Top ten episodes of care for the non-IDD Waiver population by age categories, January–December 2013

Episode of care	Non-IDD Waiver (comparison group)			
	< 18 years	> 19 years	Total	% of Total
Condition related to treatment—medical/surgical	68	43,084	43,152	71.7
Musculoskeletal	286	33,282	33,565	55.8
Hypertension	20	24,304	24,324	40.4
Cardiovascular	141	21,642	21,782	36.2
Pulmonary	345	19,856	20,201	33.6
Neurological	453	19,724	20,177	33.5
Diabetes	22	19,493	19,515	32.4
Dermatologic disorders	140	17,362	17,501	29.1
Nephrology/renal	112	16,192	16,301	27.1
Mental health	206	15,835	16,041	26.7

Sum of age group totals may not equal total if recipients turned nineteen part way through report period and had an event when eighteen and again when nineteen

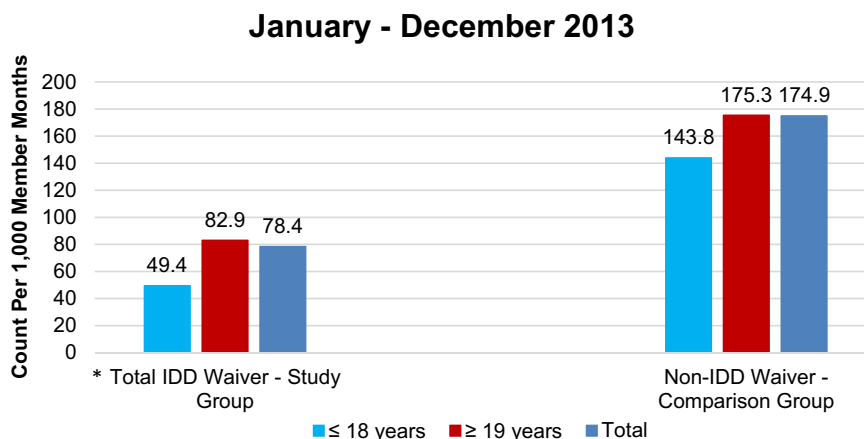
IDD Intellectual and developmental disability

(40.4%), cardiovascular (36.2%), and pulmonary (33.6%) episodes (Table 3). Mental health (26.7%) episodes were the 10th most frequent episode for the control group. For both groups, comparing age distributions for individuals under 18 years of age and older than 18 years of age, the majority of cases were in the adult category.

The IDD Waiver group had fewer emergency department (ED) admissions (78.4 per 1000 member months (MM)) than the comparison group (174.9 per 1000 MM), ( $p=0.05$ ) (Fig. 1). Similarly, the IDD Waiver group had a lower rate of inpatient admissions (67 per 1000 MM) compared to the Non-IDD Waiver group (126 per 1000 MM). (Fig. 2). While the rate of inpatient admissions for the Non-IDD Waiver group was higher for both adults and children, and the rate of admissions for children was higher in each group than

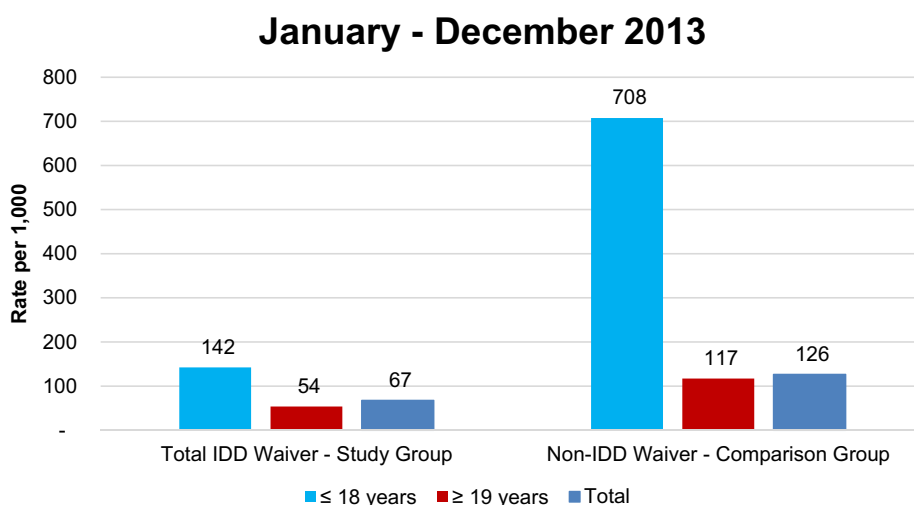
the rate for adults. The rate for children in the Non-IDD Waiver group was significantly greater (708 per 1000 MM) than all other subcategories. Furthermore, patients with an inpatient readmission within 30 days of discharge was lower for the IDD Waiver group (12 per 1000 MM) than for the Non-IDD Waiver group (30 per 1000 MM). Similar to the experience with hospital admissions, children in both the study group and the comparison group had higher rates of hospital readmission within 30 days of discharge than the adults in the respective group, with children in the Non-IDD Waiver group having a significantly higher rate of readmissions (265.7 per 1000 MM) (Fig. 3). However, the percentage of patients receiving preventative care in 2013 was similar throughout both the study and comparison group, with

**Fig. 1** Number of emergency department visits per 1000 MM, January–December 2013



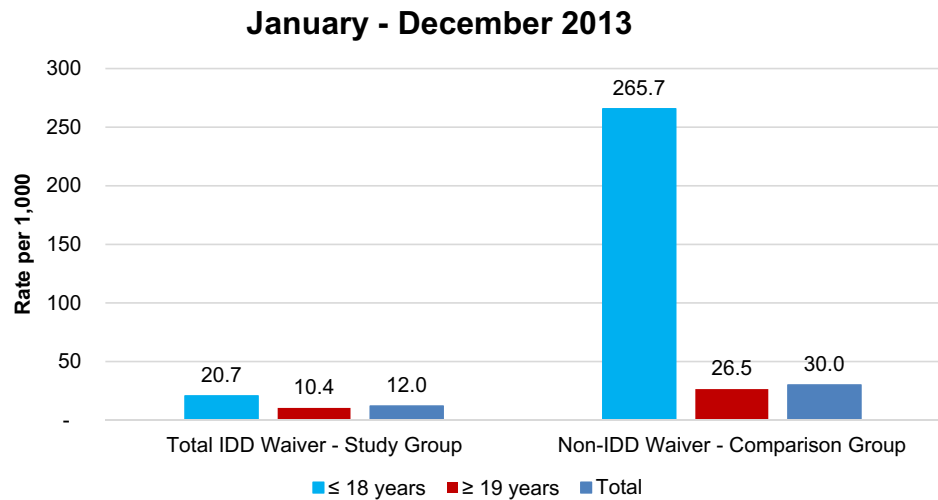
*Abbreviations:* IDD Waiver groups — Individual Options (IO)Waiver, Level 1, Self Waiver and Transition Waiver. \*Total IDD Waiver significantly different from total Non-IDD Waiver,  $p = 0.05$ .

**Fig. 2** Rate of inpatient admissions per 1000, January to December 2013



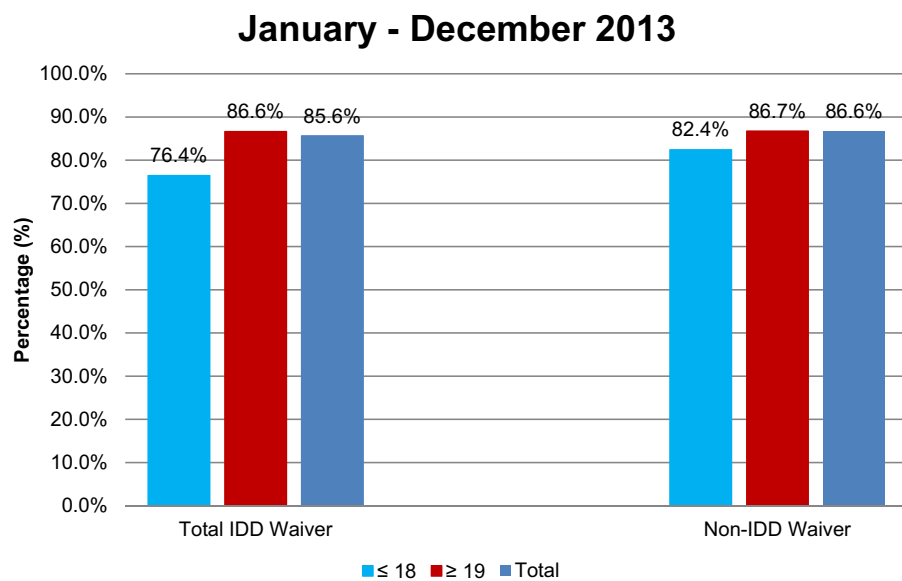
*Abbreviations:* IDD Waiver groups — Individual Options (IO)Waiver, Level 1, Self Waiver and Transition Waiver. *Notes:* 1) The number of inpatient admissions and readmissions excludes admissions for Maternity/Deliveries and Newborn admissions.  $p > 0.05$ .

**Fig. 3** Rate (per 1000) of inpatient admissions with a readmission within 30 days of discharge, January–December 2013



*Abbreviations:* IDD Waiver groups — Individual Options (IO)Waiver, Level 1, Self Waiver and Transition Waiver. *Notes:* 1) The number of inpatient admissions and readmissions excludes admissions for Maternity/Deliveries and Newborn admissions.  $p > 0.05$ .

**Fig. 4** Percent of patients receiving preventative care, January—December 2013



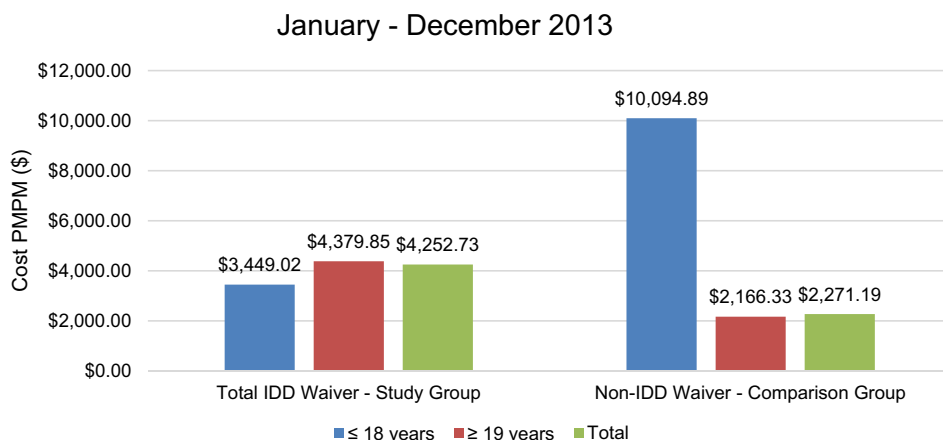
*Abbreviations:* IDD Waiver groups — Individual Options (IO)Waiver, Level 1, Self Waiver and Transition Waiver. *Notes:* 1) The number of inpatient admissions and readmissions excludes admissions for Maternity/Deliveries and Newborn admissions.  $p > 0.05$ .

an average of 86% of patients receiving preventative care (Fig. 4).

The overall Medicaid expenditures, per member per month (PMPM) by study and comparison group are shown in Fig. 5. Despite higher rates of utilization of ED and hospital, and despite larger numbers of covered individuals, the Non-IDD Waiver comparison group had lower overall Medicaid costs (\$2271 PMPM) compared to the IDD Waiver study group (\$4253 PMPM). To better understand where the costs were occurring, Medicaid expenditures

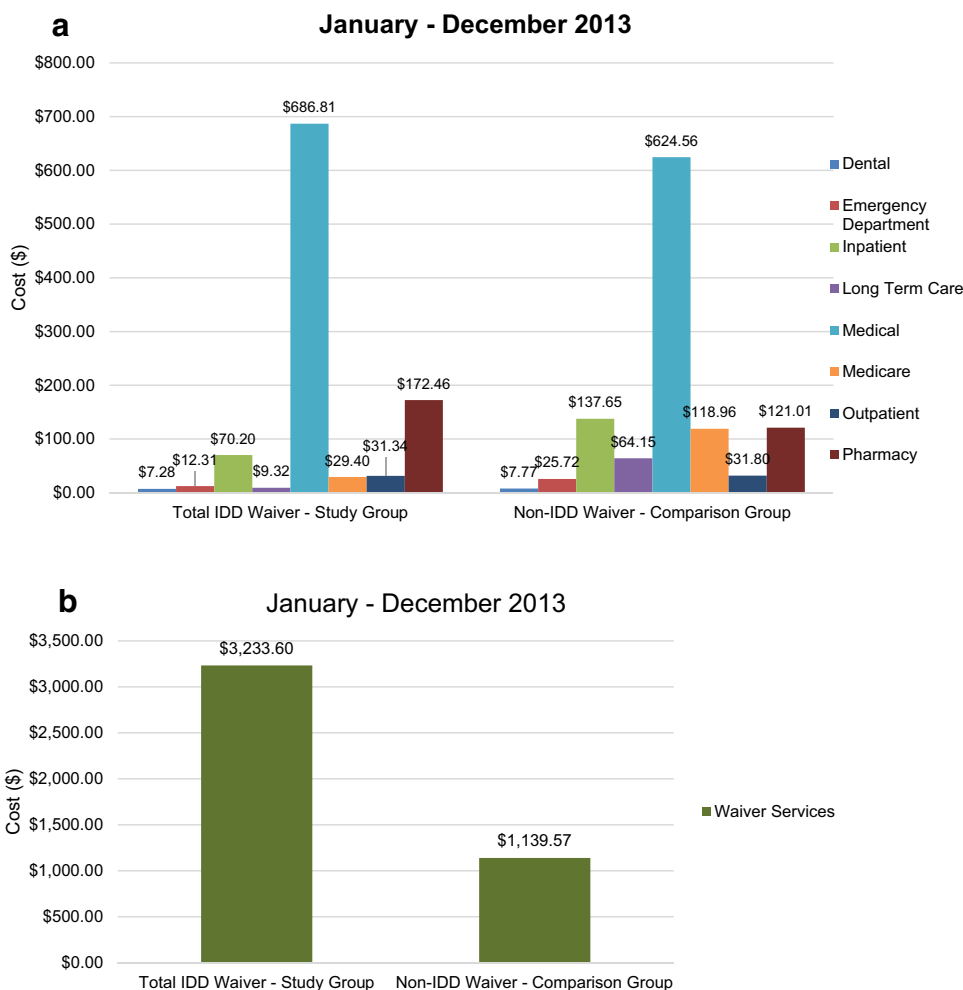
were determined by category of service. For both the study and the comparison group, waiver services (LTSS) were found to be the most costly category of expenditure, with the average expenditures for individuals in the IDD Waiver (\$3234 PMPM) almost three times those for the Non-IDD Waiver group (\$1140 PMPM) (Fig. 6b). These differences in LTSS likely reflect differences in the waiver service design (including allowed amount, duration and scope), which varies between IDD and non-IDD waiver programs.

**Fig. 5** Comparison of per member per month (PMPM) total medicaid costs (\$), January–December 2013



Abbreviations: IDD Waiver groups — Individual Options (IO)Waiver, Level 1, Self Waiver and Transition Waiver.  $p > 0.05$ .

**Fig. 6** a and b comparison of medicaid costs (\$) per member per month (PMPM) by category of service: non-IDD Waiver vs. IDD Waiver populations, ages 19 and over, January–December 2013



For non-LTSS expenditures (where benefit design does not vary between IDD and non-IDD waiver programs), the IDD Waiver group has a similar or lower expenditure than the comparison group on a PMPM basis for all but

two categories of service, including for inpatient hospital services (\$70 PMPM for the IDD Waiver group compared to \$138 PMPM for the Non-IDD Waiver group). Medical expenditures were higher for the IDD Waiver group (\$687

PMPM) compared to the control group (\$625 PMPM), as were pharmacy expenditures (\$172 PMPM for the IDD Waiver group compared to \$121 PMPM for the Non-IDD Waiver group) (Fig. 6a).

## Conclusion

Both the IDD Waiver and the Non-IDD Waiver population are high cost subpopulations within the Medicaid program. The drivers of those expenditures show important similarities and differences between the two groups. Both groups appear to have a high level of access to preventive care. In both groups, LTSS are the primary category of expenditure, though LTSS expenditures are significantly higher on a PMPM basis for the IDD Waiver population. This may reflect in large part differences in underlying waiver program design in Ohio, in terms of the allowable amount, scope and duration of waiver services, which varies significantly across the state's waiver programs. Within medical (non-LTSS) service categories, the rates of utilization (per 1000 MM) in the IDD Waiver is lower across inpatients hospital admission, readmissions within 30 days and use of ED. Expenditures for non-LTSS services are similar or lower for the IDD Waiver group in most categories, but are higher for medical services and pharmacy.

The findings in this study underscore the importance of examining population-specific data in designing healthcare delivery and care management, highlighting the importance of access to services to address neurological and mental health issues for the IDD Waiver population. Further, the lower rate of hospitalizations, rehospitalizations and the use of ED for the IDD Waiver group, as compared to another relatively high cost Medicaid subpopulation (Non-IDD Waiver group), suggests that the problem of over-utilization of these high-cost services, which is generally presumed to be an issue, may not be the most significant issue for improving service delivery, or addressing costs, for individuals in the study group.

The analysis reports on pharmacy costs for the IDD population, which has been called the most medicated subset of the population (McQuire et al. 2015; Nabhanizadeh et al 2019). It is vital that physicians are trained to accurately diagnose and treat medical and psychiatric conditions so that patients are not over-medicated; this patient population is more vulnerable to side effects of psychotropic medication (both metabolic and extra-pyramidal), and frequently have memory and cognitive deficits which are worsened by over-medication.

The study has limitations that should be acknowledged. The demographic information of the patient claims data is limited. For example, a more detailed category of age distribution is not available, and information regarding

specific living situation (e.g., is the individual living in a house or apartment—alone, with family or other housemates—or in a group home with on-site paid staff) would be useful. Furthermore, individuals with mild IDD or unspecified IDD could be underrepresented in the data because they may be less likely to participate in a waiver program.

Also, the results of this study do not explain why certain outcomes are observed. It is unclear whether lower rates of emergency department visits, hospital admissions, and rehospitalizations within 30 days reflect a higher quality of care, the value of case management and/or the role of residential support staff often imbedded within IDD Waiver programs, or underlying differences in the health status of the respective waiver participants. While the IDD Waiver group experienced higher PMPM for medical and pharmacy services, the nationally observed higher rates of preventable mortality, comorbidities and chronic medical and psychiatric conditions in the IDD population raise questions as to whether the observed rates still reflect underutilization or lack of effectiveness in diagnosis and treatment.

Further research to understand the chronic conditions associated with the IDD population needs to be undertaken and disseminated. Identification of best practices for preventive care and treatment specific to IDD would likely improve early detection and accurate diagnosis and treatment interventions for multiple medical conditions.

## Future Direction

We have developed the Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities (CERIIDD) dedicated to the efficacy of data analysis and future research to monitor trends of utilization, cost of care and long-term services and supports with Medicaid claims data in Ohio. We would like to advance the knowledge in health care management for individuals with IDD across other states in the US. Future research is needed to determine how well the IDD system is meeting the needs of this population. This research identifies further studies needed to delve deeper into the data to fully understand the medical and behavioral conditions that impact the IDD population and to identify health system improvements that support improved quality of life. The authors to acknowledge the support and assistance of Ohio Provider Resource Association.

**Funding** No funding resources were declared for this research.

## Compliance with ethical standards

**Conflicts of interest** The authors have no conflicts of interest relevant to the content of the article.

## References

- Ailey, S. H., Johnson, T., Fogg, L., & Friese, T. R. (2014). Hospitalizations of adults with intellectual disability in academic medical centers. *Intellectual and Developmental Disabilities, 52*, 187–192.
- Bauer, A., Taggart, L., Rasmussen, J., Hatton, C., Owen, L., & Knapp, M. (2019). Access to health care for older people with intellectual disability: A modelling study to explore the cost-effectiveness of health checks. *BMC Public Health, 19*(1), 706. <https://doi.org/10.1186/s12889-019-6912-0>.
- Brameld, K., Spilsbury, K., Rosenwax, L., Leonard, H., & Semmens, J. (2018). Use of health services in the last year of life and cause of death in people with intellectual disability: A retrospective matched cohort study. *British Medical Journal Open, 25*(2), e020268. <https://doi.org/10.1136/bmjopen-2017-020268>.
- Centers for Disease Control and Prevention. National Center for Health Statistics, Department of Health and Human Services. NCHS Data Brief No. 291, Nov 2017. [cdc.gov](http://cdc.gov) Access date April 2019.
- Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. NCCDPHP, Oct 2019. [cdc.gov](http://cdc.gov) Access date May 2020.
- Grier, E., Abells, D., Casson, I., Gemmill, M., Ladouceur, J., Lepp, A., et al. (2018). Managing complexity in care of patients with intellectual and developmental disabilities: Natural fit for the family physician as an expert generalist. *Canadian Family Physician, 64*(Suppl 2), S15–S22.
- Hosking, F., Carey, I., Shah, S., Harris, T., DeWilde, S., Beighton, C., et al. (2016). Mortality among adults with intellectual disability in England: Comparisons with the general population. *American Journal of Public Health, 106*(8), 1483–1490.
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 117*, 442–454.
- McQuire, C., Hassiotis, A., Harison, B., & Pilling, S. (2015). Pharmacological interventions for challenging behaviour in children with intellectual disabilities: A systematic review and meta-analysis. *BMC Psychiatry, 26*(15), 303. <https://doi.org/10.1186/s12888-015-0688-2>.
- Nabhanizadeh, A., Oppewal, A., Boot, F. H., & Maesfesten, D. (2019). Effectiveness of medication reviews in identifying and reducing medication-related problems among people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities, 32*(4), 750–761.
- Potvin, L. A., Fulford, C., Ouellette-Kuntz, H., & Cobigo, V. (2019). What adults with intellectual and developmental disabilities say they need to access annual health examinations: System navigation support and person-centred care. *Canadian Family Physician, 65*(Suppl 1), S47–S52.

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.