

# Investigating Interactions between Long-Term Services and Supports (LTSS) and Healthcare for Individuals with Intellectual and Developmental Disabilities (I/DD)

August, 30 2018

National Home & Community Based Services Conference

---

MARYSE AMIN, PHD, MS

BARBARA EDWARDS, MPP

VIKKI WACHINO, MPP

PATRICIA LYONS, PHD, LISW-S



# Gaining an Understanding of Individuals with I/DD

- State Medicaid policy is increasingly focused on obtaining improved value for high cost, complex populations
  - Improve health outcomes
  - Control costs to assure sustainability of the program
- States seeking integration of services across physical, behavioral and LTSS
- Often turning to managed care arrangements to achieve system reforms – but less often for individuals with I/DD



# Inclusion in Managed Care arrangements for Individuals with I/DD

Enrollment for individuals with I/DD in managed care for acute care services<sub>1</sub>:

Always Excluded	Always Mandatory	Always Voluntary	Varies
8	11	4	16

Total states = 39

Enrollment for individuals with I/DD in managed care for LTSS services:

Always Excluded	Always Mandatory	Always Voluntary	Varies
3	7	5	8

Total states = 23



# Concern over Costs and Outcomes for Individuals with I/DD

- Cradle to grave relationship with Medicaid for individuals with I/DD – results in significant lifetime costs
- Healthcare cost for Individuals with I/DD are higher on a per person basis<sub>2</sub>
  - From average annual costs (national) for supported living services (\$27,590) to average annual costs (national) for state operated I/DD institutional care in larger facilities (\$256,400)
- Disability is a risk factor for health disparities
  - Average life expectancy for individuals with I/DD is 66 years of age, versus the general population, 79.8 years.<sup>3,4</sup>
  - Individuals with I/DD are often socioeconomically disadvantaged
  - Health system often poorly prepared to serve individuals who have I/DD



# What works for Individuals with I/DD?

- Are the health system problems the same for the I/DD population as for other users of LTSS?
- What are the health access and outcome disparities for the I/DD population(s)?
- What role does the system of LTSS/specialty services play in achieving improved outcomes?
- What strategies are most effective to achieve improvements in health outcomes? In quality of life, including independence, self-determination and community integration? Do strategies need to vary across the lifespan or by sub-populations?
- Is traditional managed care the answer or are there other models of care that are needed?





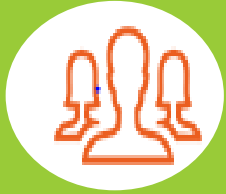
Center for Epidemiological Research for Individuals  
with Intellectual and Developmental Disabilities

Using Data to Transform Lives

## **Our Mission:**

Using healthcare and long term services and supports (LTSS) data to improve the quality of lives and health care of individuals with intellectual and developmental disabilities (I/DD) while reducing costs.





Understand healthcare needs, become independent self-advocates



Address health disparities, understand impact of LTSS, remediate gaps in population health



Determine cost of care across Medicaid continuum, design outcome based reimbursement systems



Develop tailored outcome driven care plans, drive services where needed

**Using Data to Transform the Lives of 7.3M<sub>5</sub>**



# Meet one of our Inspirations!





# A life self-determined or a self-determined life

## 1987 - 2000

- Diagnosed with Meconium Aspiration Syndrome (APS); predicted lifespan of 5 hours
- Eating, but not self-feeding at age 5, told may never walk or talk
- Mother quit job to care for son and needed financial assistance through Medicaid
- Child welfare referral due to *inappropriate behaviors* exhibited in school; multiple suspensions; doctor said to “accept as is”
- Middle school years and a concerned teacher, finally introduced to DD specific services

## Today: 2018

- Individuals with I/DD are living into their senior years
- Through advance technology and integration of research aimed at addressing the needs of individuals with I/DD, mobility and communication are individually
- Medicaid is the largest funder of healthcare and health related services to individuals with I/DD
- I/DD specific research has contributed to increased clinical knowledge and practices within HCBS



# Awareness about Individuals with I/DD, have we done enough?



Born in 1987



Born in 2015 to Sesame Street

Born in 2017 to Gerber



# Evaluation of Ohio Medicaid data for Individuals with Intellectual and Developmental Disabilities

---



# Research Objective

## **Purpose:**

Evaluate the current state of healthcare services for individuals with I/DD in Ohio (FFS).

## **Objective:**

Determine the healthcare profile of individuals with I/DD, their healthcare expenditures and how individuals with I/DD compare to other Medicaid populations.



# Methods

- Collaborated with the Ohio Department of Developmental Disabilities (ODODD) and the Ohio Department of Medicaid (ODM) to obtain Ohio Medicaid claims data.
- A business associate agreement was obtained with ODM.
- Obtained de-identified Medicaid claims data by ICD-9-CM diagnosis codes for variables categorized by patient and provider demographics and type of healthcare services.
- Research met requirements of HIPAA and all business associate agreements.



# Total Medicaid expenditures for HCBS waiver services in Ohio

Study Group

Population in 4 I/DD Waivers in Ohio

(*n* = 34,599)

Adults and children

Comparison Group

Population in Non-I/DD Waivers in Ohio

(*n* = 60,182)

Adults and children



# Data Criteria and Key Variables

## Data Criteria:

- Medicaid coverage between January - December 2013
- Stratified by age (child  $\leq$  18 yo vs. adult  $\geq$  19 yo)
- Categorized by healthcare services

## Key Variables:

- Utilization of Outpatient / Inpatient/ ED visits
- Overall Cost Analysis
- ED / Hospital / Outpatient / Dental / Pharmacy costs
- 41 Episodes of care summary groupings
- County (88) specific data by providers



# Results

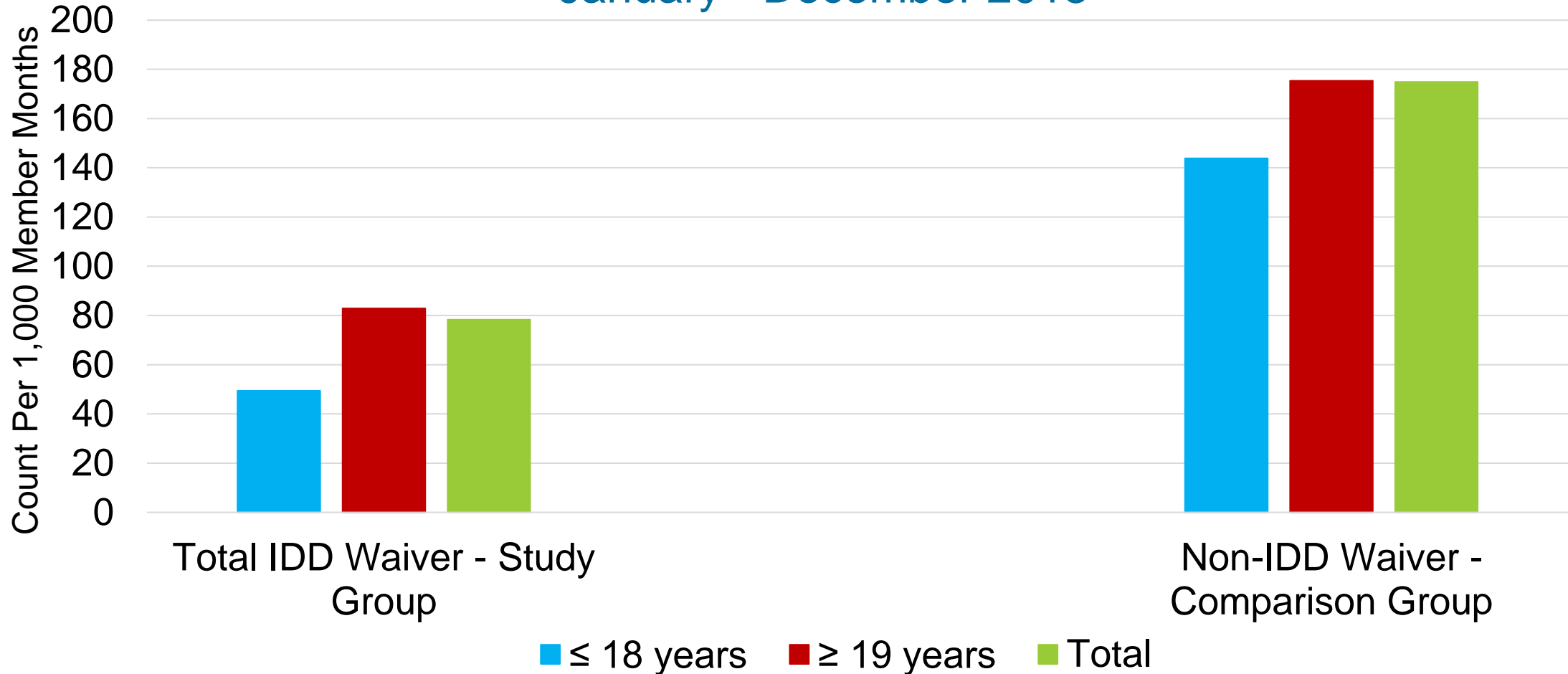
---





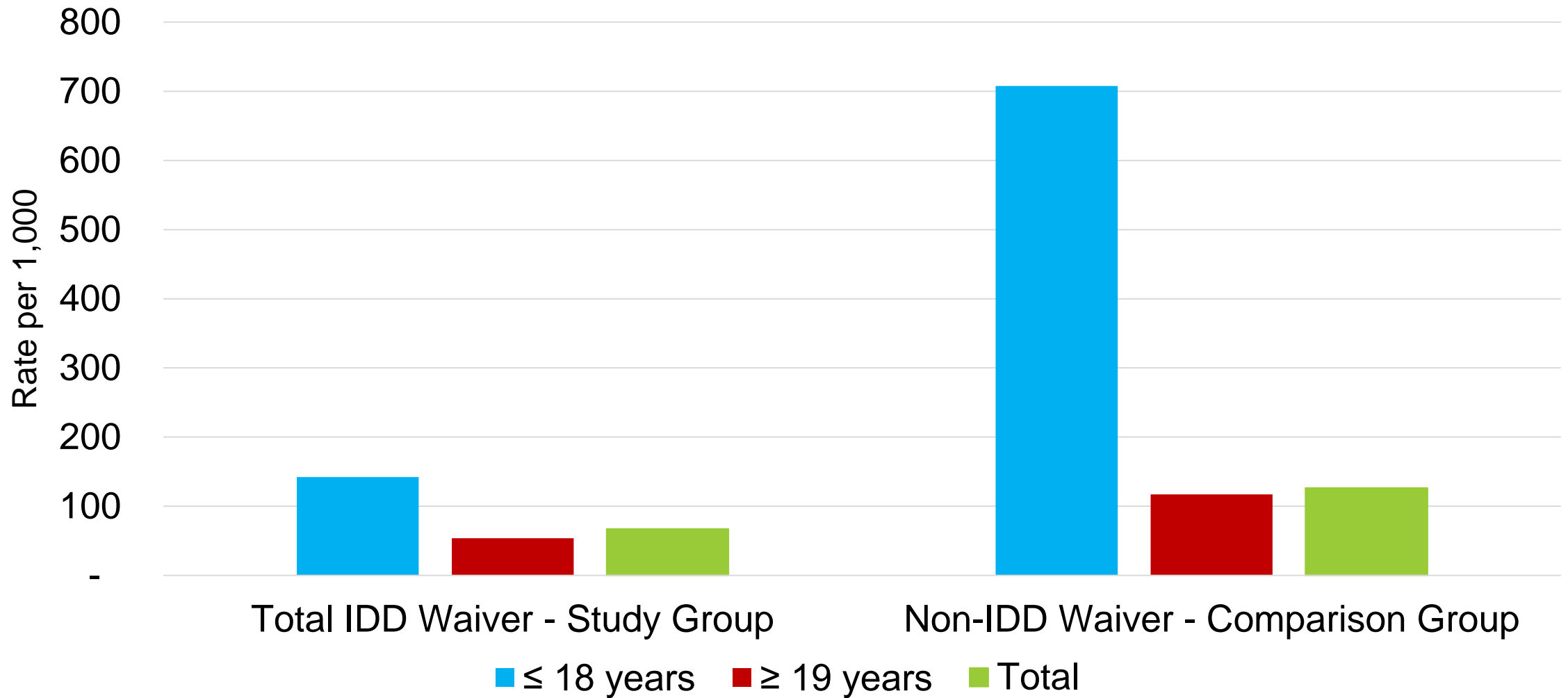
# Emergency Department Visits Per 1,000 Member Months

January - December 2013



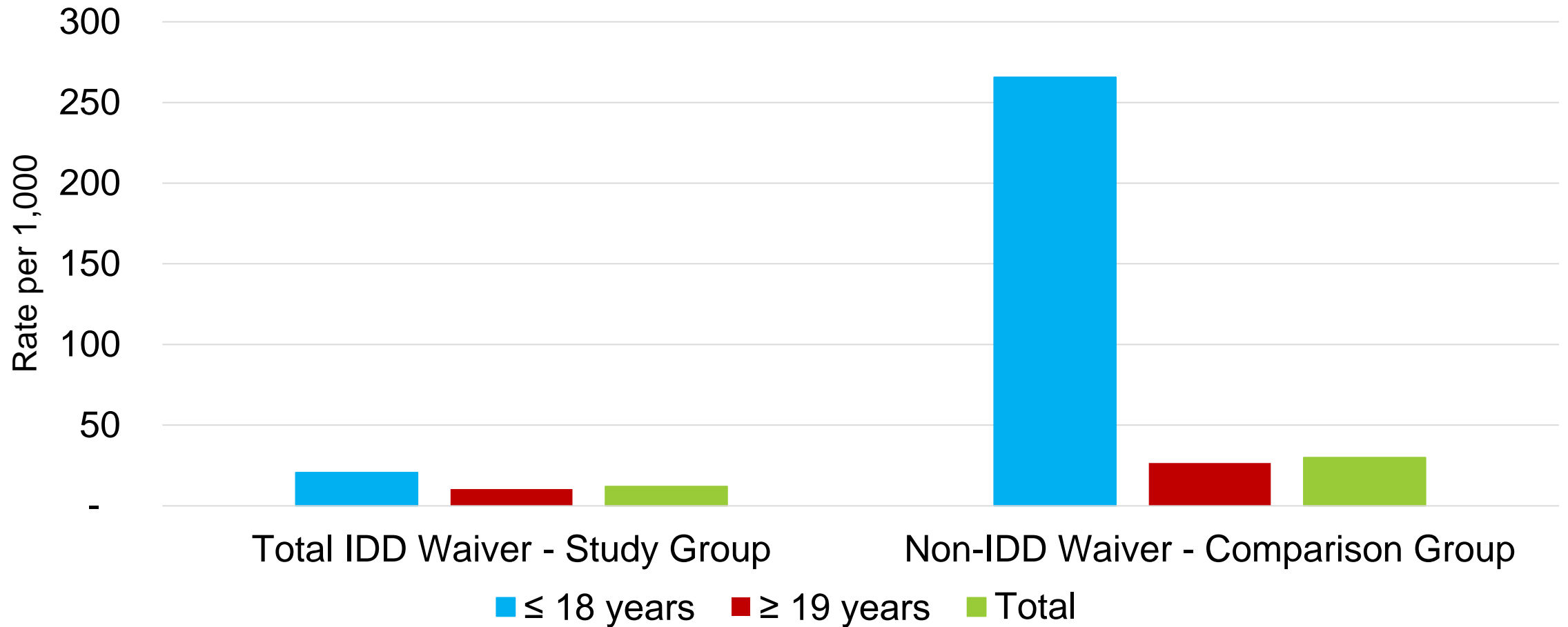
# Rate of Inpatient Admissions

January - December 2013



# Rate of Inpatient Admissions with a Readmission within 30 days of Discharge

January - December 2013



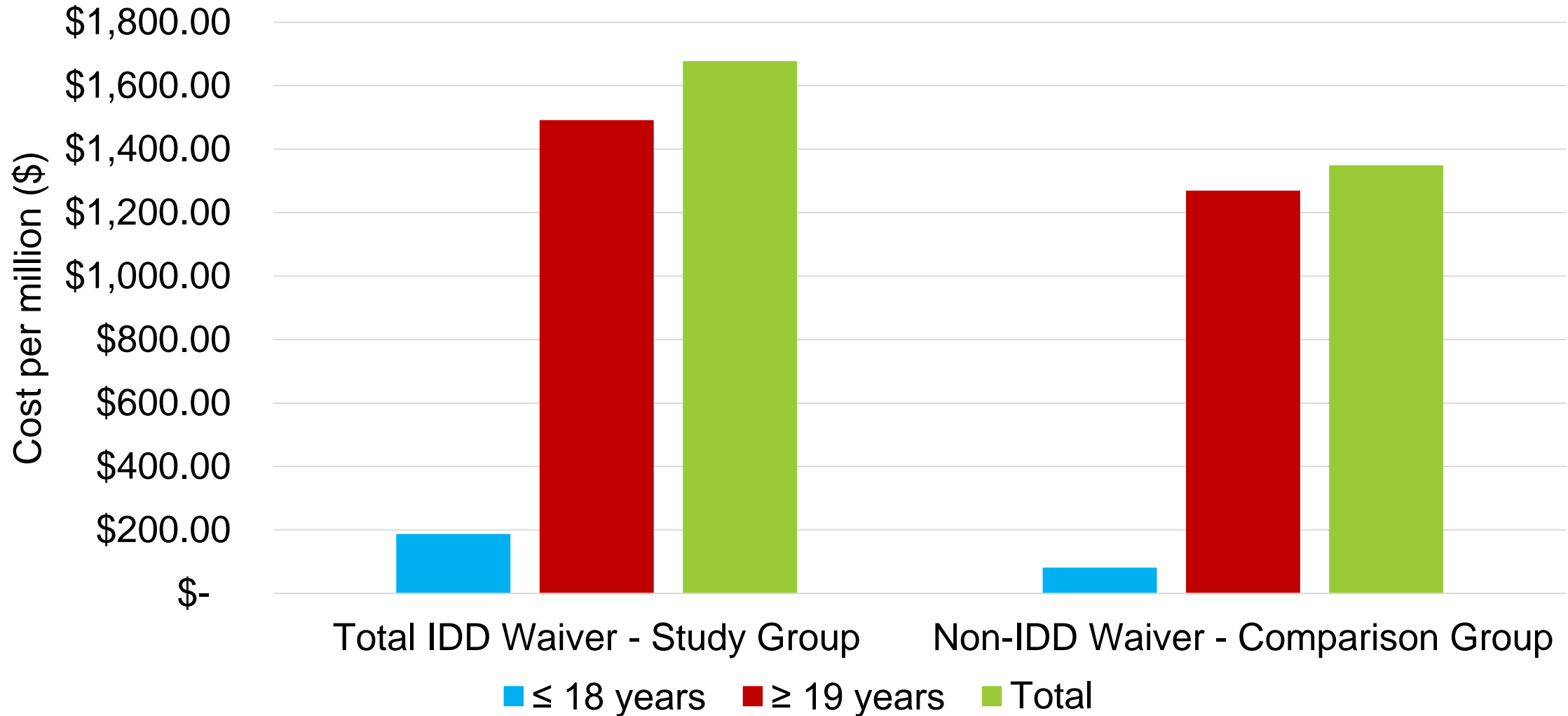
# Top 10 Episodes of Care sorted by I/DD waiver groups

Episode Summary Group	IDD Waivers (Study Group)	Non-IDD Waivers (Comparison Group)
Neurological	94.1%	33.5%
Mental Health	52.8%	26.7%
Musculoskeletal	34.8%	55.8%
Otolaryngology Related	27.1%	17.0%
Ophthalmology	23.3%	25.1%
Dermatologic Disorders	23.0%	29.1%
Gastrointestinal	20.0%	25.6%
Pulmonary	15.4%	33.6%
Immunology/Allergy	19.1%	21.4%
Nephrology/Renal	11.9%	27.1%



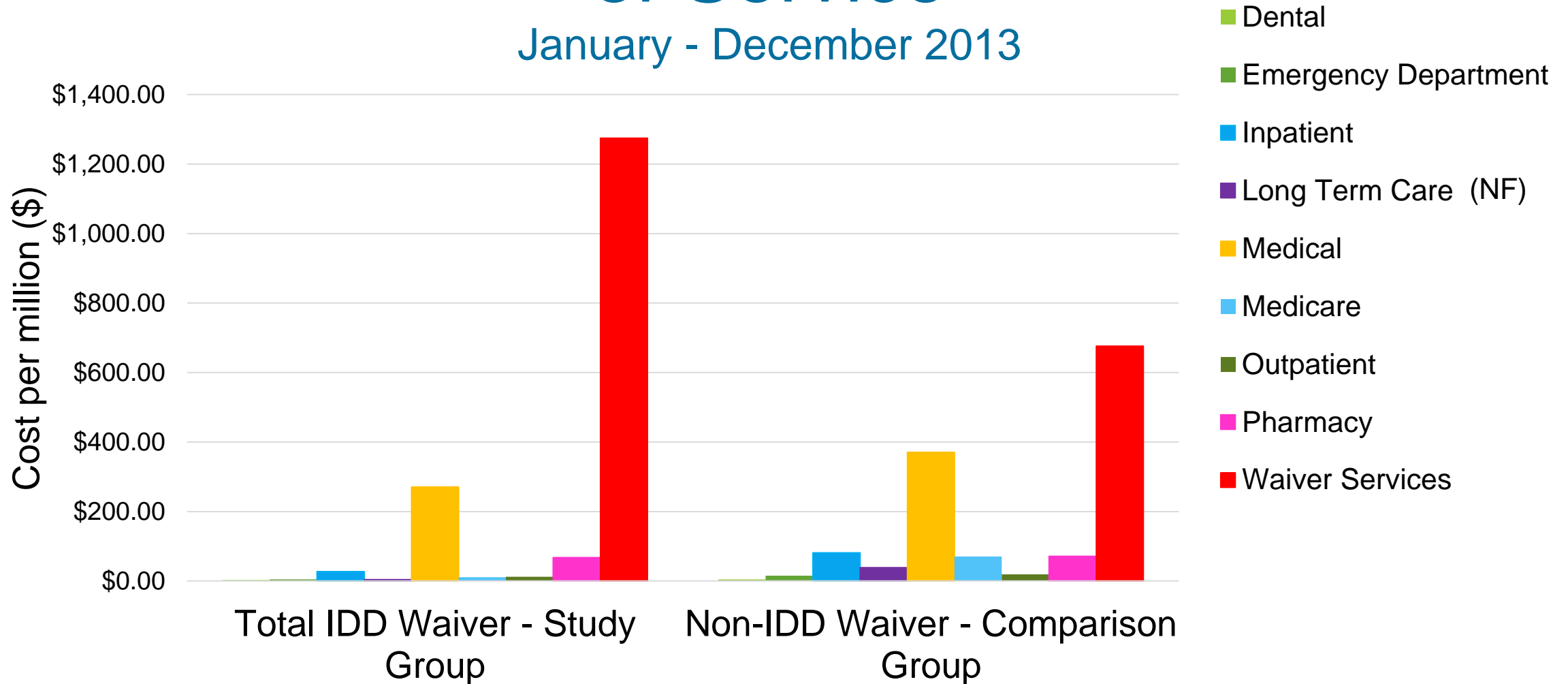
# Total Medicaid Costs

January - December 2013



# Total Medicaid Costs by Category of Service

January - December 2013



# Conclusion

- Most common episodes of care for individuals with I/DD included neurological and mental health conditions.
- Total Medicaid costs were greater for the I/DD waiver group versus the Non-I/DD waiver group.
- However, the rates of use of high expenditure services such as emergency department visits, hospitalizations and re-hospitalizations were lower for the I/DD waiver group than for the non-I/DD waiver group.
- The majority of costs for the I/DD waiver group are concentrated to waiver expenditure.



# Limitations

- Variability in case definitions
- Cost analysis not complete cost for service expenditure for dual eligible individuals (where Medicare is primary payer for hospitalization, use of ED, pharmacy, physician services)
- More thorough analysis of data needed to determine which specific neurological procedures are most costly versus most common





# CERIIDD Moving Forward

- Evidence-based research used to guide quality of healthcare
- Aims based on research to improve health outcomes and increase effectiveness of care
- Need for research examining social determinants of health for individuals with I/DD
- Focus on areas of greatest potential impact
  - E.G., Medical costs, pharmacy costs, and inpatient utilization for individuals under 18
- Through long-term data surveillance and evaluation, establish benchmarks for I/DD population healthcare costs (PMPM) and determine most common chronic conditions specific to individuals with I/DD to improve treatment and overall health outcome



# References

- 1) Kaiser 50 State Medicaid Budget Survey 2017-2018
- 2) State of the States in DD, University of Chicago, 2015 data
- 3) <https://www.cdc.gov/nchs/>, 2016
- 4) Coppus, A M.W. (2013); People with Intellectual Disability: What do we know about adulthood and life expectancy? *Developmental Disability Review*. 18, 6-16.
- 5) <https://globenewswire.com/news-release/2018/06/11/1519884/0/en/The-Arc-Releases-2017-FINDS-Survey-Data-on-Caregiving-for-People-with-Intellectual-and-Developmental-Disabilities-I-DD.html>
- 6) Traci, MA, Seekins, T, Szali-Petree, A, Ravesloot, C. Assessing secondary conditions among adults with developmental disabilities. A preliminary study. *Mental Retardation*. 2002; 40(2):119-131.
- 7) Reichard, A, Stolze, H, Fox, MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and Health Journal*. 2011;4:59-67.
- 8) Morgan, JP, Minihan, PM, Stark PC, Yantsides, KE, Park, A, Nobles, CJ, Must, A. The oral health status of 4,732 adults with intellectual and developmental disabilities. *Journal of the American Dental Association*. 2012; 143(8):838-846.
- 9) Ohio Department of Developmental Disabilities (ODODD)
- 10) Ohio Department of Medicaid.(ODM)



# Questions?

---

