

2022

SOAR Partners IDD Waitlist Research

Kester Muthalaly
Oral Roberts University

Victoria Mayes
Oral Roberts University

Tochukwu Onwuakpa
Oral Roberts University

Joshua Borger
Oral Roberts University

Jane Malcolm
Oral Roberts University

Follow this and additional works at: https://digitalshowcase.oru.edu/cob_grad_works



Part of the [Business Commons](#)

Recommended Citation

Muthalaly, Kester; Mayes, Victoria; Onwuakpa, Tochukwu; Borger, Joshua; and Malcolm, Jane, "SOAR Partners IDD Waitlist Research" (2022). *College of Business Graduate Student Works*. 1.
https://digitalshowcase.oru.edu/cob_grad_works/1

This Article is brought to you for free and open access by the College of Business at Digital Showcase. It has been accepted for inclusion in College of Business Graduate Student Works by an authorized administrator of Digital Showcase. For more information, please contact digitalshowcase@oru.edu.



SOAR PARTNERS

TEAM TITAN



Table of Contents

- 01. I/DD WAITING LIST
- 02. REIMBURSEMENT RATE MATCH
- 03. THE "BEST IN CLASS"
- 04. CAREGIVER SALARY
- 05. TECHNOLOGY
- 06. MONEY SPENT OVERALL
- 07. POSSIBLE RESOLUTIONS



Where did we find our sources?



Kaiser Family Foundation



AARP



State Government
Websites



US Census Bureau



Bureau of Labor Statistics



EBSCO Host

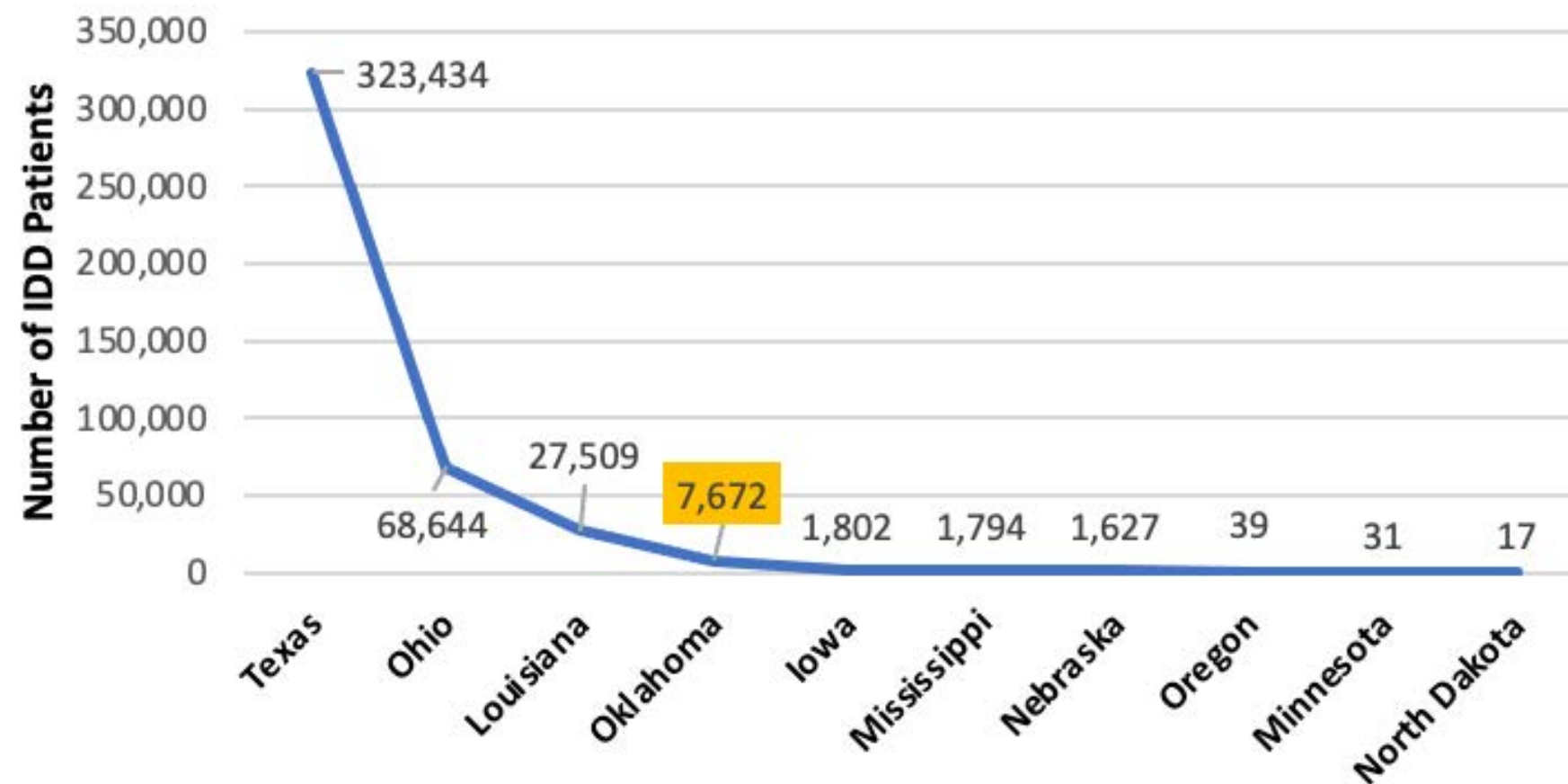


The I/DD Waiting List

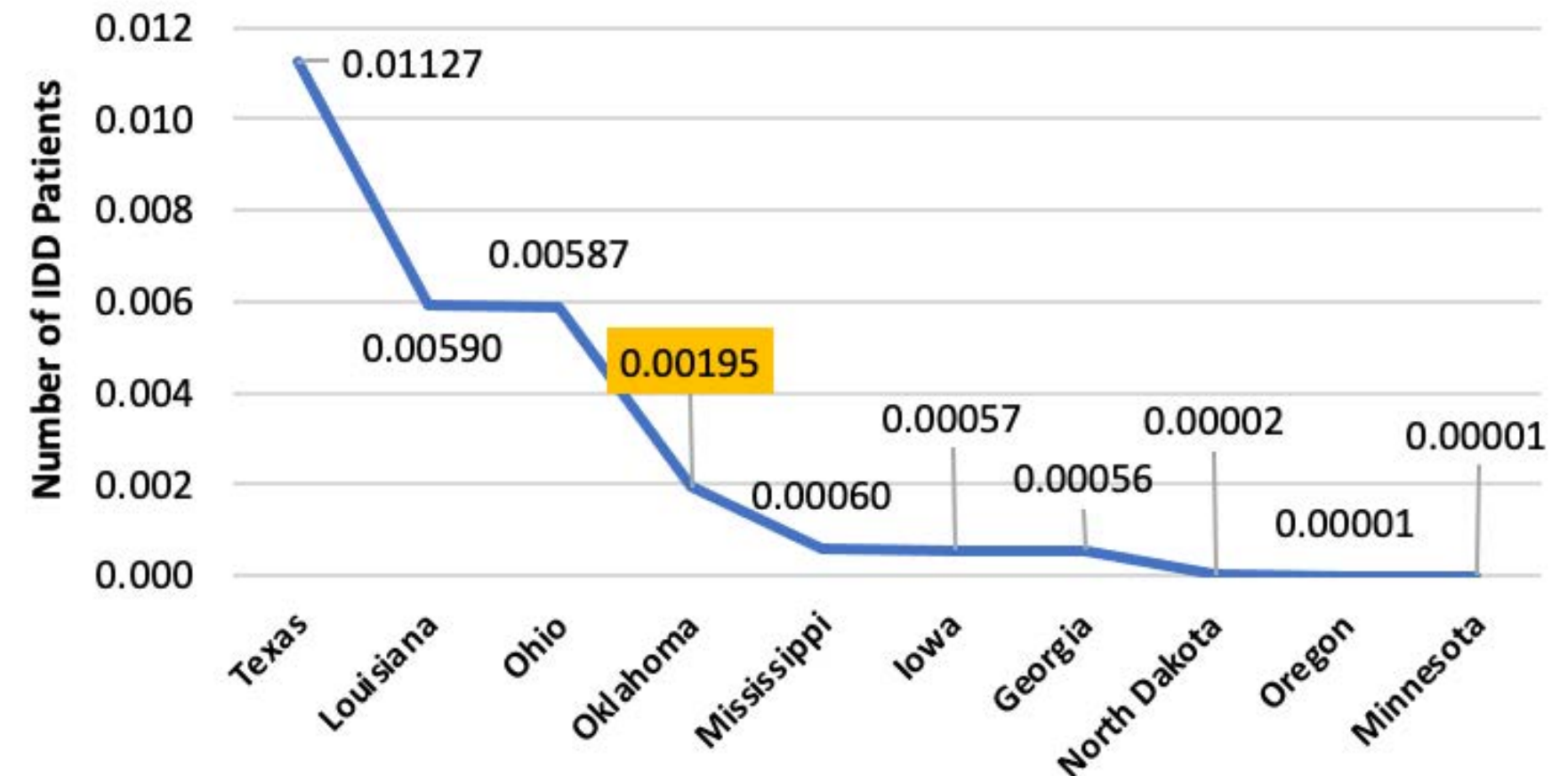



I/DD Waiting List for Selected States

U.S. States Ranked by IDD (Overall)



U.S. States Ranked by IDD (Per Capita)





The Reimbursement Rate Match





Reimbursement Rate Match

HOW DO STATES RECEIVED FEDERAL FUNDING?

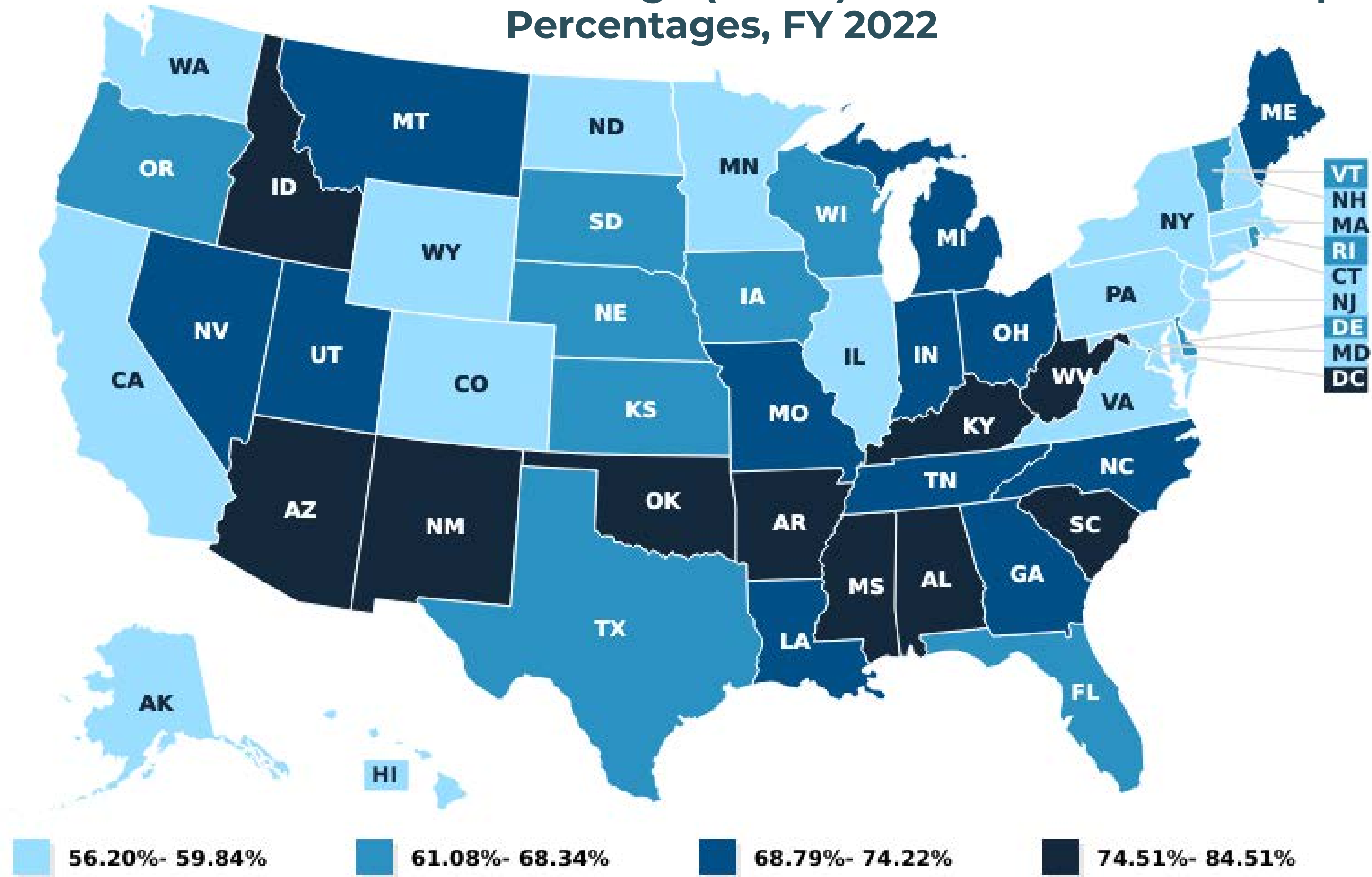
Formula based on
average per capita
income

COMPARISON

Oklahoma has FMAP
of 74.51% while
California has one of
56.20%

(Kaiser Family Foundation, 2021)

Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier: FMAP Percentages, FY 2022



SOURCE: Kaiser Family Foundation's State Health Facts.



The "Best In Class"



BEST IN CLASS

Arizona ranked #1 in the nation for services provided to the I/DD community.

Best In Class Characteristics:

- Wages & Compensation
- Community-Based Living v. Leadership Institute



(United Cerebral Palsy & Ancor Foundation, 2019)

FIRST PLACE - PHOENIX

- Healthcare institute designed as an apartment complex that cares for adults with autism
- An 81,000 square foot, \$15 million project
- Over 50 apartments; 24/7 support and classes at Gateway Community College in Phoenix



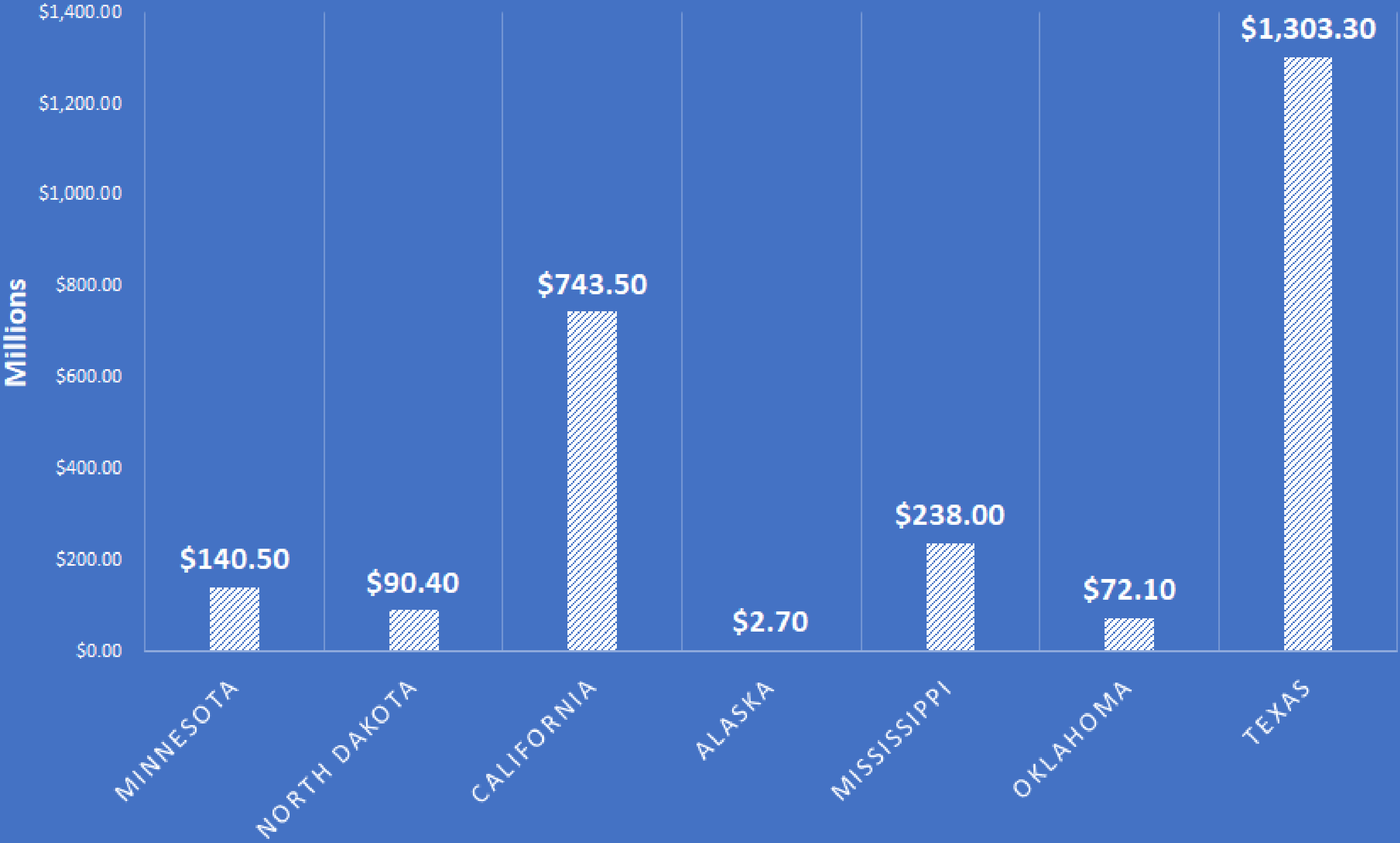
(Reagor, 2018)



How much money spent overall?

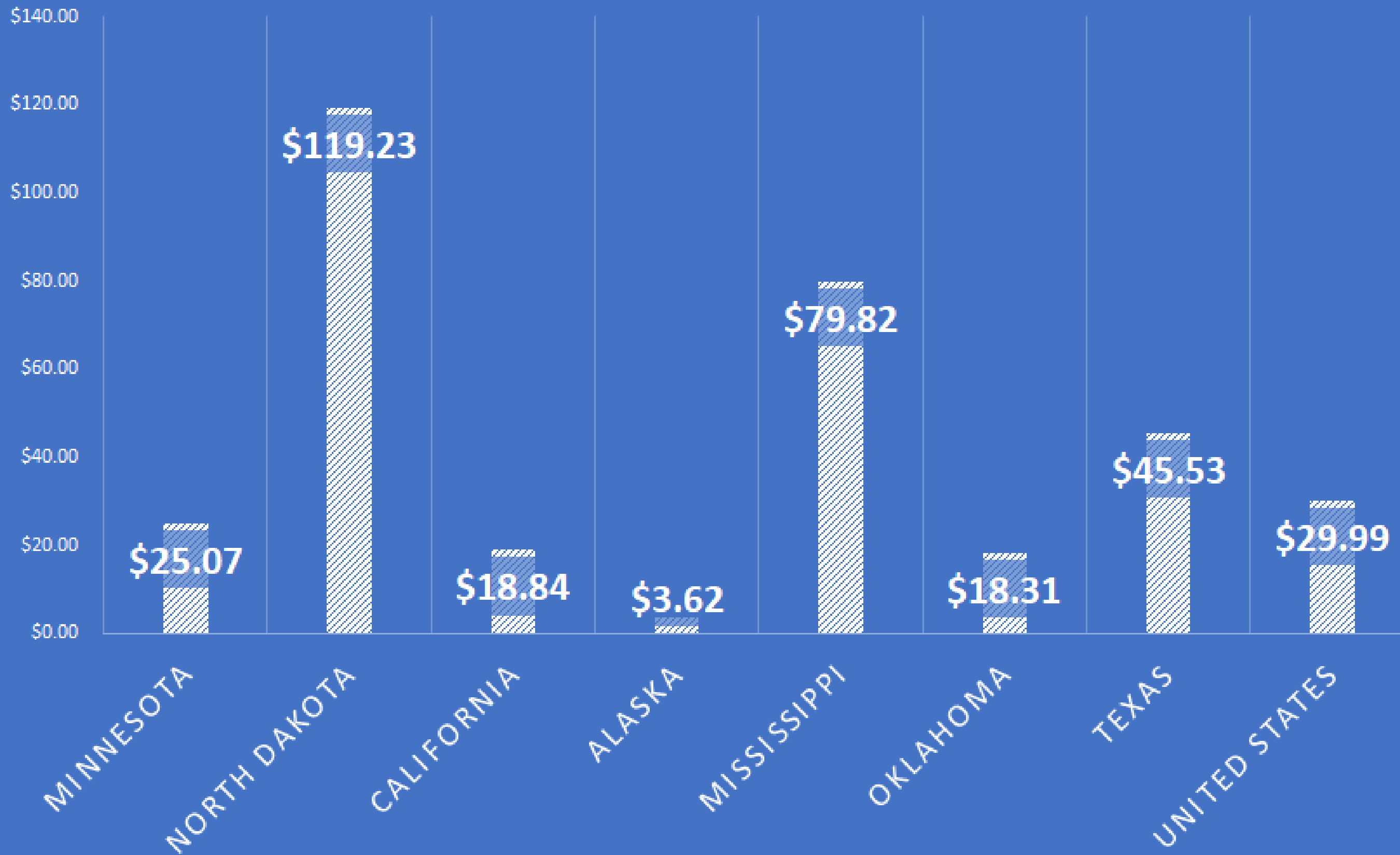


TOTAL EXPENDITURES



2018 I/DD
Total State
Expenditures

EXPENDITURES PER RESIDENT



2018 I/DD State Expenditures Per Capita

(Murray, 2021)



Family Support

I/DD FAMILY LIVING

72% of people with I/DD lived with family caregivers, including siblings

SPENDING

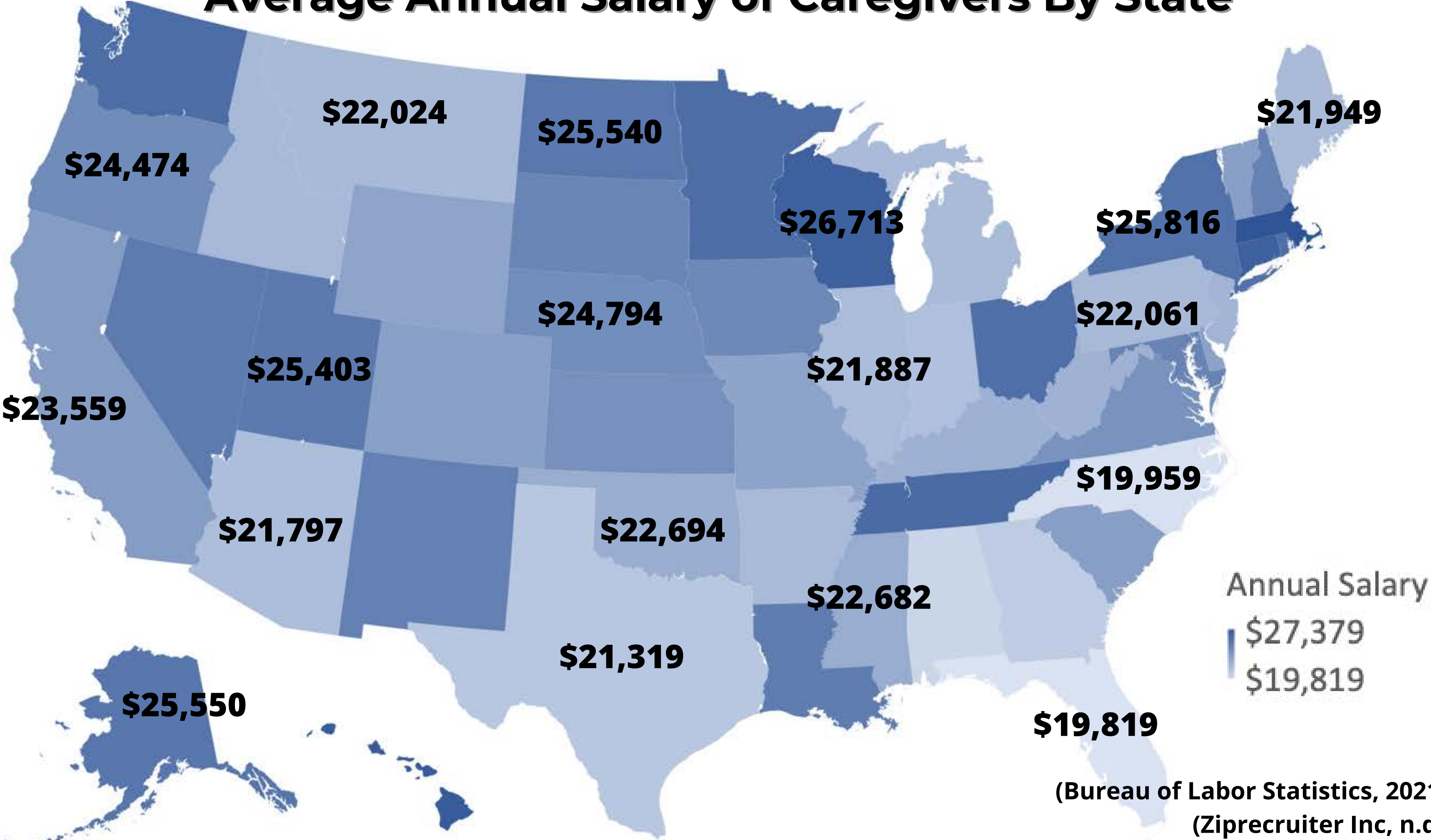
Family support expenditures = 9.5% of total I/DD spending in 2017



Caregiver Salary

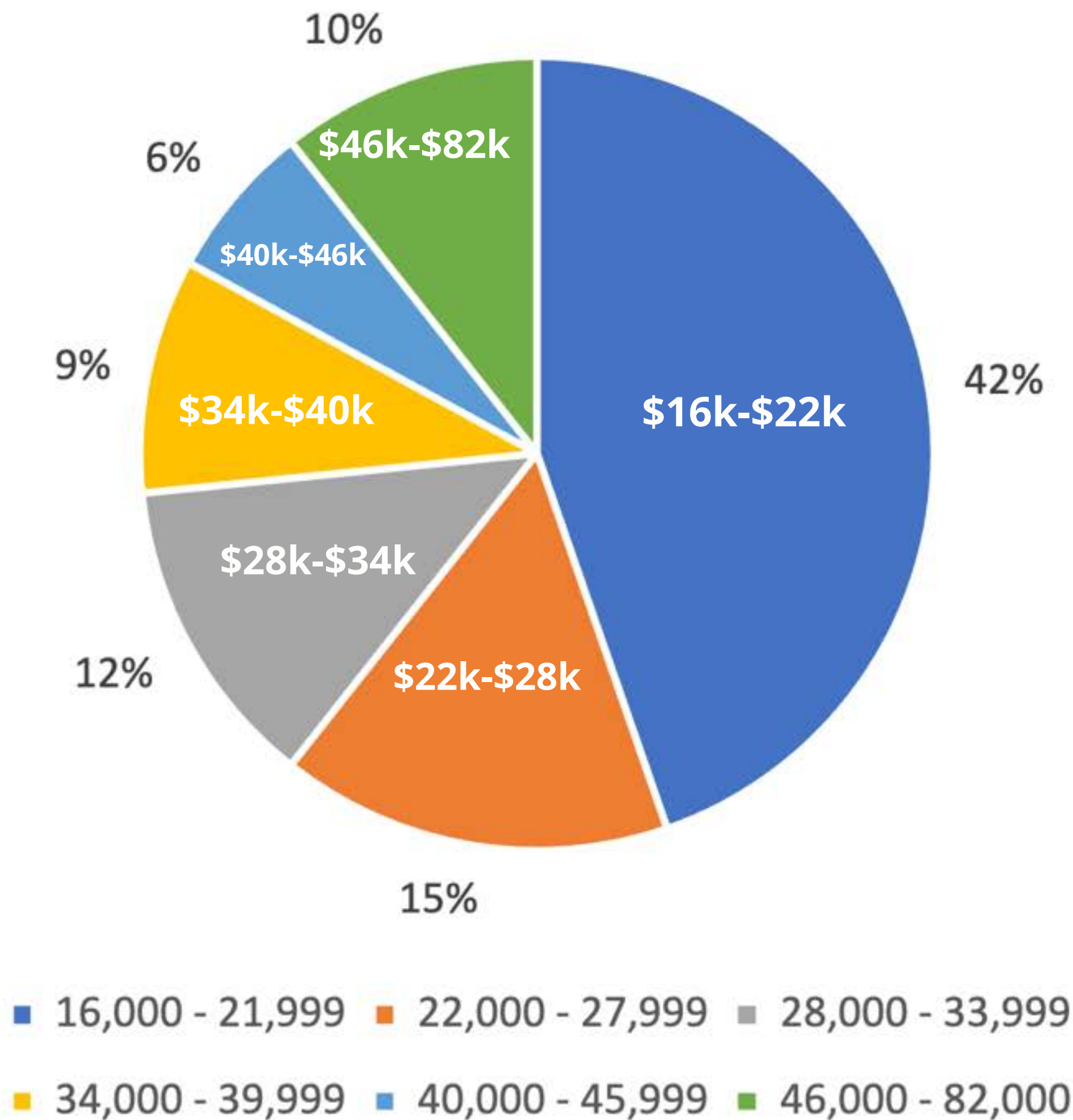


Average Annual Salary of Caregivers By State

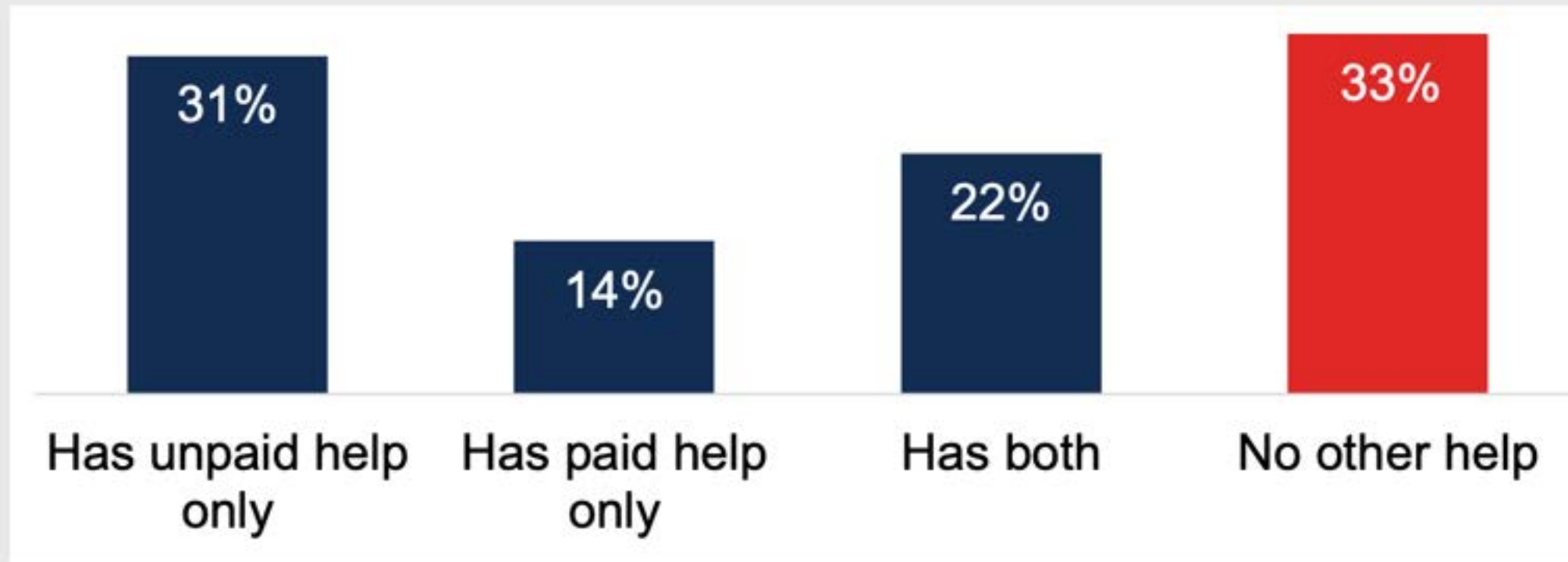


(Bureau of Labor Statistics, 2021)
(Ziprecruiter Inc, n.d.)

How much do IDD caregiver jobs pay per year?



Unpaid Caregivers



Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

Q30. (If recipient not in nursing home or assisted living) During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help them?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)



EXHIBIT A1 Matrix Heat Map: Overall Ranking

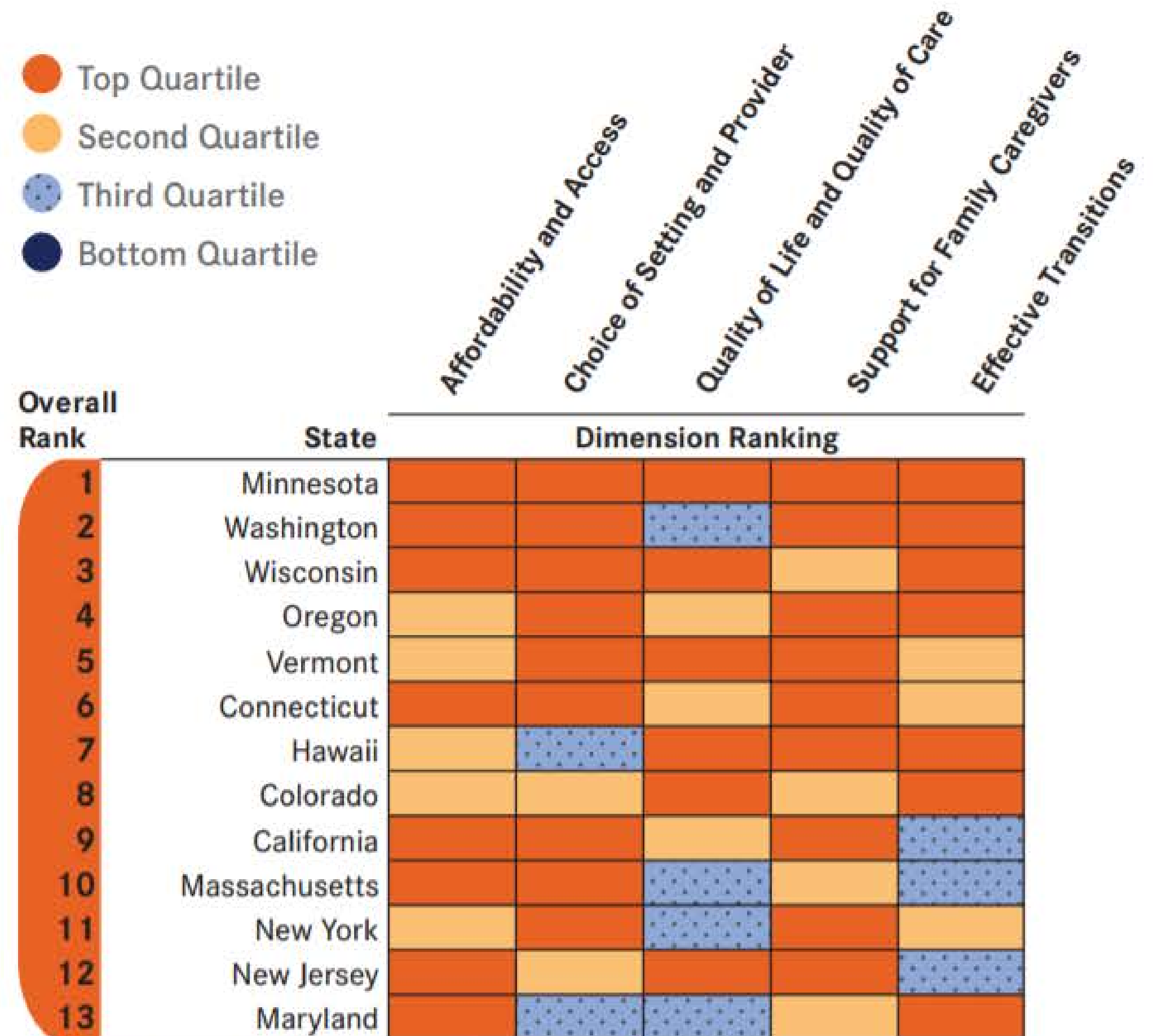
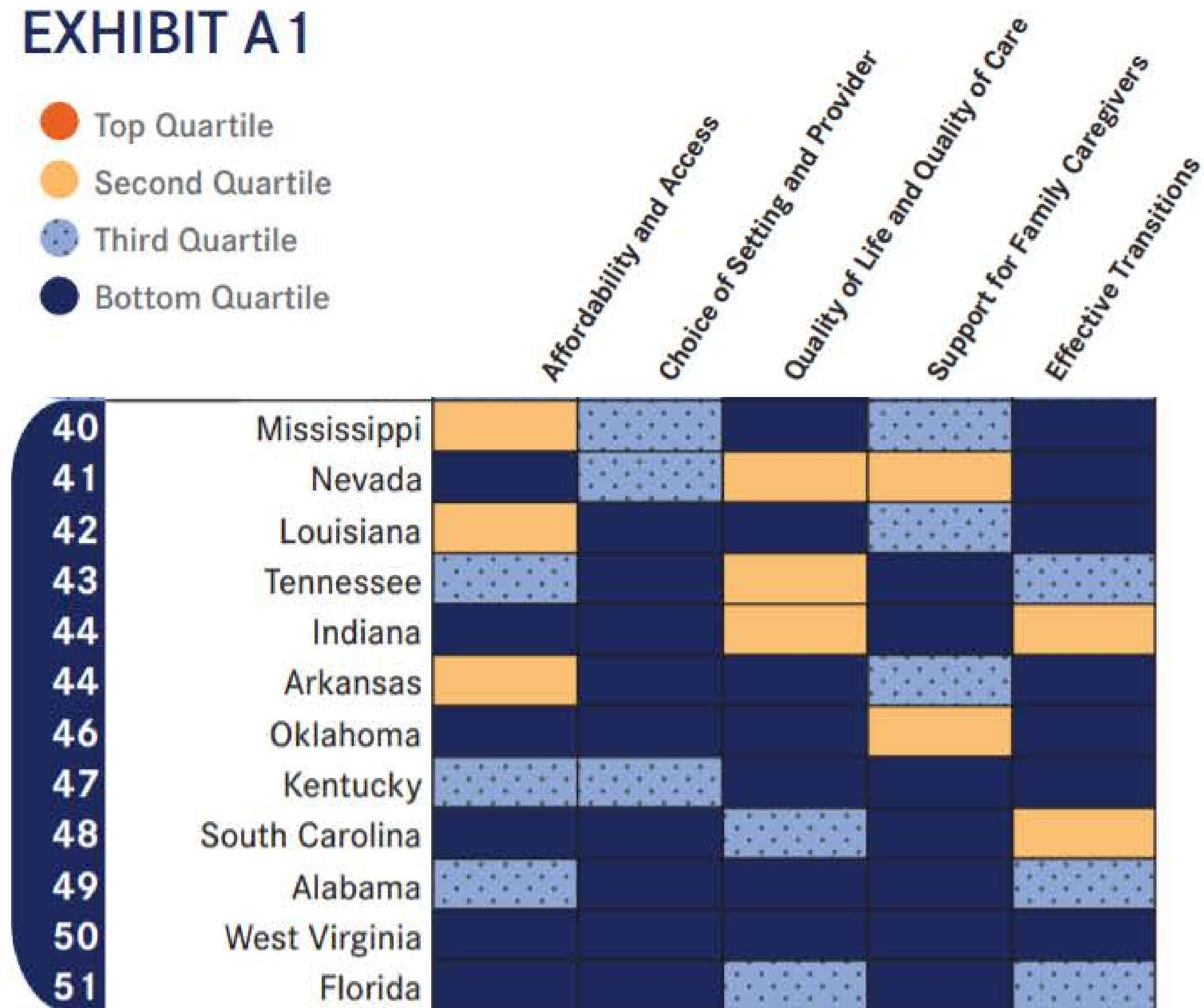


EXHIBIT A1

- Top Quartile
- Second Quartile
- Third Quartile
- Bottom Quartile



Source: Long-Term Services and Supports State Scorecard, 2020.

(AARP, 2020)

Oklahoma

- **Affordability and Access:** Bottom Quartile
- **Choice of Setting and Provider:** Bottom Quartile
- **Quality of Life and Quality of Care:** Bottom Quartile
- **Support for Family Caregivers:** Second Quartile
- **Effective Transitions:** Bottom Quartile

(AARP, 2020)

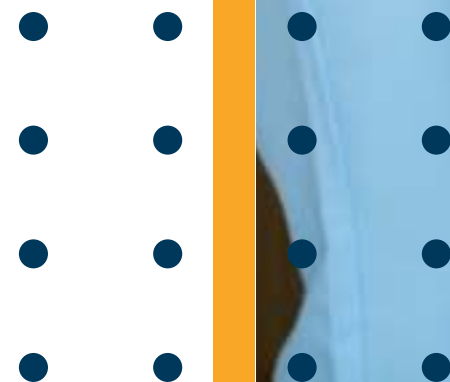
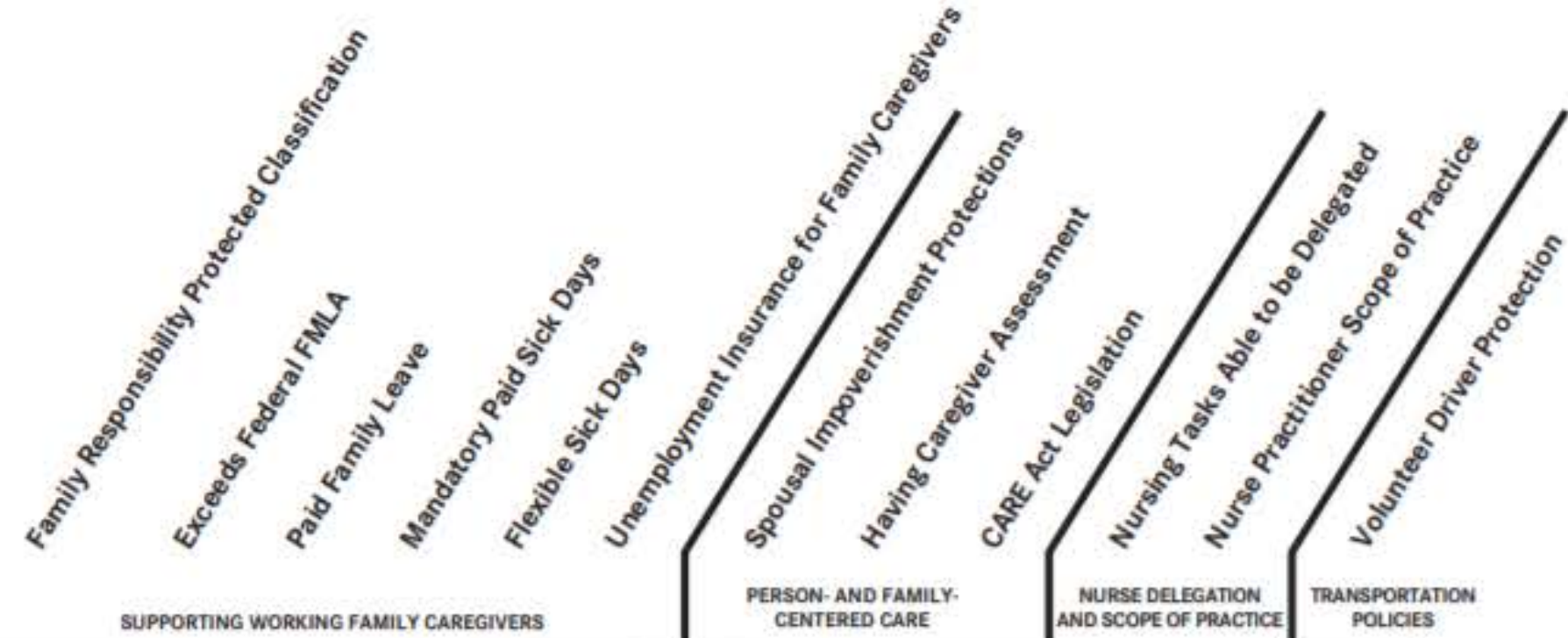


EXHIBIT A5 Matrix Heat Map: Support for Family Caregivers

Level of Policy Adoption

- High
- Moderate
- Low
- None or Minimal



Rank	State	Family Responsibility Protected Classification	Exceeds Federal FMLA	Paid Family Leave	Mandatory Paid Sick Days	Flexible Sick Days	Unemployment Insurance for Family Caregivers	Spousal Impoverishment Protections	Having Caregiver Assessment	CARE Act Legislation	Nursing Tasks Able to be Delegated	Nurse Practitioner Scope of Practice	Volunteer Driver Protection
1	District of Columbia	High	High	High	Moderate	Moderate	High	None or Minimal	High	High	Low	High	None or Minimal
2	Washington	None or Minimal	None or Minimal	High	High	High	Moderate	High	High	High	High	High	None or Minimal
3	Oregon	Low	High	Low	High	Moderate	High	Low	High	High	High	High	None or Minimal
4	New Jersey	Moderate	Moderate	Low	High	Moderate	None or Minimal	Low	Low	High	High	Moderate	None or Minimal
5	New York	Moderate	None or Minimal	High	Moderate	Moderate	High	Moderate	Low	High	Moderate	Moderate	None or Minimal
6	Minnesota	None or Minimal	Low	None or Minimal	Moderate	High	Moderate	High	High	High	High	High	None or Minimal
7	Vermont	Moderate	Moderate	High	High	High	Moderate	Moderate	Moderate	High	High	High	High
8	California	Moderate	None or Minimal	Moderate	High	High	High	None or Minimal	High	High	Low	None or Minimal	High
8	Hawaii	None or Minimal	High	None or Minimal	None or Minimal	Moderate	High	Moderate	High	High	Moderate	High	None or Minimal
10	Rhode Island	None or Minimal	Low	Moderate	High	Low	High	Low	Moderate	High	None or Minimal	High	High
11	Connecticut	Moderate	Moderate	Low	Moderate	Low	High	Low	Moderate	High	Low	High	None or Minimal
12	New Mexico	Low	None or Minimal	None or Minimal	Low	High	None or Minimal	Low	Low	High	High	High	None or Minimal
13	Arizona	Low	None or Minimal	None or Minimal	Moderate	High	High	Low	Moderate	High	Moderate	High	None or Minimal
14	Maryland	Moderate	None or Minimal	None or Minimal	High	Moderate	None or Minimal	Low	None or Minimal	High	Moderate	High	High
14	Massachusetts	None or Minimal	None or Minimal	Moderate	High	Low	High	Low	Moderate	High	Low	High	None or Minimal
16	Maine	Low	Moderate	None or Minimal	Low	Low	High	Moderate	None or Minimal	High	Low	High	High
17	Illinois	Moderate	None or Minimal	None or Minimal	Moderate	High	High	Moderate	Low	High	Low	Moderate	None or Minimal
17	Wisconsin	Moderate	Low	None or Minimal	None or Minimal	Low	High	Moderate	Moderate	None or Minimal	High	Moderate	None or Minimal
19	Nevada	None or Minimal	None or Minimal	None or Minimal	Moderate	None or Minimal	High	Low	Low	High	Moderate	High	None or Minimal
20	Colorado	Low	None or Minimal	None or Minimal	None or Minimal	High	Moderate	Low	Low	High	High	High	None or Minimal
21	Texas	Low	None or Minimal	None or Minimal	Low	None or Minimal	High	Moderate	Moderate	High	High	High	None or Minimal
22	New Hampshire	None or Minimal	None or Minimal	None or Minimal	None or Minimal	High	Low	Low	Moderate	Moderate	Moderate	High	High
23	Michigan	Moderate	None or Minimal	None or Minimal	Moderate	None or Minimal	Low	Low	Low	High	Moderate	High	None or Minimal
24	Alaska	None or Minimal	None or Minimal	None or Minimal	None or Minimal	High	High	None or Minimal	High	High	High	High	None or Minimal
24	Oklahoma	Low	None or Minimal	None or Minimal	None or Minimal	High	Moderate	High	High	Moderate	High	High	None or Minimal
26	Nebraska	None or Minimal	None or Minimal	None or Minimal	None or Minimal	None or Minimal	Low	High	High	High	High	High	None or Minimal

Oklahoma

- **Family Responsibility Protected Classification:** Low Policy Adoption
- **Unemployment Insurance for Family Caregivers:** High Policy Adoption
- **Spousal Impoverishment Protection:** Moderate Policy Adoption
- **Having Caregiver Assessment:** High Policy Adoption
- **CARE Act Legislation:** High Policy Adoption
- **Nursing Tasks Able to be Delegated:** Moderate Policy Adoption



Medicaid Caregiver Child Exemption

Under Medicaid Estate Recovery Guidelines

- **Used for recouping Medicaid expenses *after the death of Medicaid enrollee***

- An adult child can inherit parent's home if they have
 - Lived at home with aging parents for at least **2 years**
 - Cared for parent **without use of nursing home**

(Medicaid, n.d.)

(Paying for Senior Care, 2021)



Technology

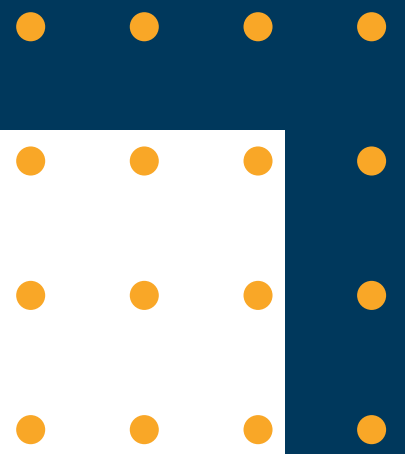


Technology Solutions

- Centralized IDD Website
 - Oklahoma.gov/IDD
 - Caregivers w/ IDD patients
 - Request medical equipment or medicine
- SOAR Researches New Cost-Efficient Medical Equipment
 - Non-profits



What are
some
possible
resolutions?





Possible Resolutions

- **Pursue Community-Based Living Facilities**
- **Increase Caregiver Salaries**
- **Create a Centralized I/DD Services Website**



THANK YOU

SOAR Partners

Executive Summary

SOAR Partners is a social impact consulting company that offers technological and professional services to institutions that strive to enhance the lives of individuals and their society. SOAR has made it a vital goal to help solve the complex issues surrounding the intellectual or developmental disability (I/DD) community. Among the many concerns the I/DD community faces across the nation, the state of Oklahoma is outstandingly behind the pack. As a response, the research conducted in this report hopes to shed light on Oklahoma's alarming waitlist and whether a solution exists.

Oklahoma's Waitlist Compared to Other States (Overall & Per Capita)

When comparing the overall list of I/DD patients on the waitlist in all the states across the nation, Oklahoma is not amongst the worst states in this regard. It ranks 12th with over 7,600 patients on the waitlist, which is smaller than states closer to the top, with states like Texas and Ohio reporting vast numbers of 323,434 and 68,644, respectively (Kaiser Family Foundation, 2018). While this may seem to paint Oklahoma in a good light, the population also has to be considered. Oklahoma has a population of about 3.9 million people (United States Census Bureau, 2021). Thus, when the I/DD waitlist is compared on a per capita basis, Oklahoma jumps up to 7th on the list, leapfrogging states with a significantly higher population like Florida and Pennsylvania. This is a clear indication that the waitlist is still a significant issue for the state of Oklahoma regardless of its relatively "smaller" number of overall individuals.

Oklahoma's Medicaid Reimbursement Rate Match Compared to Other States

The Kaiser Family Foundation compiles a federal medical assistance percentage (FMAP) table for 2022 that reveals percentages of how much the Federal government will match state

Medicaid expenditures (Kaiser Family Foundation, 2021). A selected number of states are included below from a full table on Kaiser Family Foundation.

2022 Federal Medical Assistance Percentage (FMAP) for Medicaid	
States	FMAP Percentages
Mississippi	84.51%
Oklahoma	74.51%
Texas	67.00%
Alaska	56.20%
California	56.20%
United States	56.20%
Source: KFF 2021	

Oklahoma receives a high FMAP percentage, which corresponds with the medical reimbursement rate, so the Federal government allocates more money to Oklahoma to “reimburse Medicaid recipients” (Centers for Medicare & Medicaid Services, n.d.). The Federal government matches a minimum of 50% expenditures to states, so wealthier states such as California and New York have FMAPs of 56.20% (Peter G. Peterson Foundation, 2021). States with higher taxes can provide more Medicaid services, explaining how California can have few people on their I/DD waitlist (KFF, 2018).

“Best in Class” States in I/DD Services (Costs & Benefits)

One might assume that higher funding equates to improved services for the I/DD community. While this is true to a degree, it is not a comprehensive solution. Maine reported the highest spending in the nation with \$11.65 per \$1,000 of personal income, more than triple that of California, which has lower waitlist numbers on an overall and per capita basis (Tanis et al., 2020). While Arizona does not have section 1915(c) waivers, it provides similar services to I/DD patients. According to the annual Case for Inclusion Report, Arizona ranks number one in providing services to the I/DD community in the nation. A significant reason is that Arizona

focuses its spending on providing community-based living rather than institutional living for its patients.

An example of these living spaces is the new health care institute called FirstPlace Phoenix. It is an 81,000 square foot project designed to cater to individuals with autism assisting them to live more independently. It has 55 apartments, a residential training program, and a leadership institute for medical professionals and researchers (Reagor, 2018).

Across the nation, DSPs (Direct Service Professionals) have voiced their displeasure with the compensation received for their services. According to the annual Case for Inclusion Report, over 87% of respondents cited inadequate pay as their reason for leaving, which only hurts the quality of service provided to I/DD patients. States like Wisconsin have established agencies to clear career pathways by providing built-in wage increases to improve retention.

Average Compensation for Caregivers to the I/DD Community (State-by-State)

A meaningful conversation among the I/DD community of caregivers is the topic of salary. Unfortunately, the numbers reveal that caregivers are often overlooked and unappreciated in terms of compensation. According to the Bureau of Labor Statistics, caregivers' average wage per year is about 27 thousand (2021). Among all caregivers in the United States, sixteen percent specifically care for those with developmental disabilities. The state of Oklahoma ranks relatively close to the national average at a median income of 22 thousand a year for caregivers (Ziprecruiter Inc, n.d.). The majority of caregivers are caring for family members and are forced to pay reparations (NAC and AARP, 2020). Many family caregivers cannot effectively support their loved ones without adequate help from governmental services such as Medicaid; This has proven to be a significant issue across the nation.

A 2020 long-term services and supports (LTSS) state scorecard includes an overall ranking matrix heat map portraying the LTSS effectiveness for each state (AARP, 2020). Minnesota ranked the highest state overall, scoring in the top quartile for affordability and access, choice of setting and provider, quality of life and quality of care, support for family caregivers, and effective transitions. From Long Term Scorecard's studies, the 2020 overall ranking heat map ranked Oklahoma as the bottom 46th state (AARP, 2020). Oklahoma was in the bottom quartile for each category listed above except support for family caregivers, where Oklahoma was listed in the second quartile. Long Term Scorecard ranked Oklahoma 24th on another heat map of support for family caregivers, tying with Alaska for a moderate level of policy adoption (AARP, 2020). Oklahoma was on the high level of policy adoption for CARE Act legislation (AARP, 2020).

Technology Utilized by Other States to Link Caregivers and Funding to Support the I/DD Community

Understanding the needs of I/DD patients with the potential of underfunded caregivers, Oklahoma could create a centralized website to better link caregivers with the I/DD community. An I/DD specific website accessed through Oklahoma.gov would be highly beneficial to the I/DD community as well as for family members who would like to easily access I/DD services covered by the state of Oklahoma. The \$164 million allocated to Oklahoma's Medicaid expansion from July 1, 2021 can be disbursed to family caregivers to serve I/DD patients through the website (Forman, 2021). Also, Oklahoma can provide stipends for necessary medicine or medical equipment through the website, as well. By using their resources to pay family caregivers and directly serve the needs of I/DD patients, Oklahoma can witness the waitlist reduced. SOAR can also use technology to research new cost-efficient medical equipment for

I/DD patients and become a connection between Oklahoma and non-profits to attend to the specific needs of I/DD patients.

I/DD State Expenditures on Average and Comparatively vs. Oklahoma (Overall & Per Capita)

Due to a lack of data, expenditure reports for the states are only available up until 2017 and 2018. The overall average of state spending on I/DD services is \$192.1 million (Murray, 2021). However, this average is vastly disproportionate because of the uneven distribution between the larger and smaller states. According to the Centers Medicare and Medicaid Services (CMS) report, states spent an average of \$29.99 per capita in FY 2018 (Murray, 2021). Oklahoma spent \$18.31 per capita in I/DD expenditures in FY 2018, compared to total spendings for Oklahoma equaling \$72.1 million (Murray, 2021).

For the graph below: FY 2018 Total ICF/IID Expenditures (Murray, 2021)

States	Expenditures Per Resident	Total Expenditures
Minnesota	\$25.07	\$140.5 million
Oregon	Not recorded	Not recorded
North Dakota	\$119.23	\$90.4 million
California	\$18.84	\$743.5 million
Alaska	\$3.62	\$2.7 million
Mississippi	\$79.82	\$238.0 million
Oklahoma	\$18.31	\$72.1 million
Texas	\$45.53	\$1,303.3 million
United States	\$29.99	\$9,796.3 million

Source: (*Murray, 2021*)

Conclusion

In search for a solution to Oklahoma's waitlist, the data revealed that Oklahoma has the 7th highest waiting list in the U.S. per capita (United States Census Bureau, 2021). The Medicaid reimbursement rate match showed the federal government is willing to give more money to poorer states like Oklahoma to compensate for their loss. States with the best performance had embedded community-based living situations rather than the more typical institutional settings. Oklahoma was ranked slightly below the national average for caregiver salaries.

Research revealed that more money is not always the solution. Technology is a significant contributor in the process of solving this dynamic issue. There is often not a single solution to this issue, but generally many different ways to reach a consensus. The topic of I/DD is rather complex and requires much more in-depth research to find the root issue of Oklahoma's long waitlist. However, sources such as KFF and Oklahoma.gov revealed that by partnering with family caregivers and creating a centralized I/DD website, Oklahoma can disburse the millions of their Medicaid budget sitting untouched to help people with I/DD needs and ultimately decrease the waitlist.

Research Methods Summary

Sources

- ❖ Kaiser Family Foundation (KFF): This is a nonpartisan, nonprofit organization that reports on U.S. health issues. Various fundamental statistics came from KFF for this I/DD report.
 - *2018 Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers* - table displays the number of individuals on each U.S. state's I/DD waitlist
 - Contacted the Kaiser Family Foundation and learned the 2020 statistics would be released soon, possibly by the end of the year.
 - *2022 Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier* - the FMAP percentage provides a metric to compare how much the Federal government allocates Medicaid to states by matching a various percent of the each state's Medicaid budget
- ❖ American Association of Retired Persons (AARP): This is a helpful source of information on family caregivers and I/DD information. AARP gathers information from an elderly perspective, and adults above age 65 are a major portion of people with I/DD needs.
- ❖ Long Term Scorecard: This is an AARP website that visualizes many I/DD statistics into heat maps. Long Term Scorecard's PDFs provide data on state rankings of Medicaid and family caregiver effectiveness.
- ❖ Key Coalition of Alaska: This is a non-profit advocating for Alaskans with developmental disabilities. The source contains the Key Coalition of Alaska's points in

the 2021 plan to reduce the I/DD waitlist, which explains how seeking more funding is necessary to reduce the waitlist.

- ❖ U.S. Census Bureau: The U.S. Census Bureau was crucial in finding population information for Oklahoma and other states.
- ❖ U.S. Bureau of Labor Statistics: The government website is under the U.S. Department of Labor and includes information of wages rates of caregivers for I/DD patients.
- ❖ State Government Websites: State government websites such as Oklahoma.gov were used initially in the project to grasp Oklahoma's definitions and specific measures for I/DD. When state government websites lacked information, sources such as KFF that compiled information on states were an efficient compilation of data.

Databases/Search Engines

- ❖ Eagle Search (ORU Database)
 - Title: "Waitlist" & Select Field: "Disability," sorted by Date Newest
 - Search Terms: medicaid AND (I/DD or "intellectual development*" or autism or spectrum) AND (reimbursement or payment)
 - Expanders: Apply equivalent subjects
 - Search Modes: Boolean/Phrase
- ❖ Google Advanced Search
 - mississippi AND medicaid OR reimbursement OR rate AND 2021
 - site: medicaid.ms.gov
 - I/DD state spending
 - site: medicaid.gov
 - medicaid and "I/DD" and (wait or backlog)

- site:.org

❖ Google Search

- Medicaid reimbursement rate 2021 (include state here)
- “National Alliance for Caregiving and AARP”
- “Caregiving in the US”
- Pasted question 6 directly into Google as a natural language search: “What technology is utilized by other states (especially those with lower waitlists) to better link caregivers and funding to support the I/DD community?”
 - Found MACPAC report: [Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences](#)
 - Found article from U.S. National Library of Medicine National Institutes of Health: [COVID-19 and people with intellectual disability: impacts of a pandemic](#)
- “Technology” to reduce I/DD waitlist
 - Found Alaska’s 2021 plan to reduce their I/DD waitlist from the [Key Coalition of Alaska](#)
- Oklahoma "care act" intellectual disability
 - Found source from the [Oklahoma Health Care Authority](#)

Annotated Bibliography

Introduction

SOAR Partners. (2019). *Home*. Retrieved November 15, 2021 from <http://soar.partners/>

The company website provides in-depth information regarding SOAR Partners, LLC.

SOAR is a nonprofit organization seeking to solve a social dilemma in society. The website reveals how SOAR plans to minimize the complexities that revolve around the I/DD community.

Oklahoma's Waitlist Compared to Other States (Overall & Per Capita)

Kaiser Family Foundation. (2018). Waiting list enrollment for medicaid section for 1915(c)

home and community-based services waivers. *State Health Facts*.

<https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

This article from the Kaiser Family Foundation shows the most recent health facts per state in the United States. The website has provided the number of people total who are on the waitlist for Medicaid per state.

United States Census Bureau. (2021, October 8). 2018 nation and state population estimates

[Table]. *Table 2. Cumulative Estimates of Resident Population Change for the United States, Regions, States, and Puerto Rico*. U.S. Department of Commerce.

<https://www.census.gov/newsroom/press-kits/2018/pop-estimates-national-state.html>

The US Census Bureau has provided the total US population growth per state from 2010 to 2018.

Oklahoma's Medicaid Reimbursement Rate Match Compared to Other States

Centers for Medicare & Medicaid Services. (n.d.). Comparing Reimbursement Rates. *Medical Assistance Rate*. U.S. Centers for Medicare & Medicaid Services. Retrieved November 16, 2021, from <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/understand-the-reimbursement-process>

The source explains how to properly compare reimbursement rates between states and offers using medical assistance rates as the metric. The medical assistance rates are used in the FMAP.

Kaiser Family Foundation. (2021). Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier. [Table]. <https://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/?activeTab=map¤tTimeframe=0&selectedDistributions=fmap-percentage&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

The Kaiser Family Foundation compiles a federal medical assistance percentage (FMAP) table for 2022 that reveals percentages of how much the Federal government will match state Medicaid expenditures.

The source explains how to properly compare reimbursement rates between states and offers using medical assistance rates as the metric. The medical assistance rates are used in the FMAP.

Peter G. Peterson Foundation. (2021, February 22). *How do states pay for Medicaid?*.

<https://www.pgpf.org/budget-basics/budget-explainer-how-do-states-pay-for-medicaid>

The article explains the procedure for the government matching Medicaid rates for states and the minimum amount the Federal government is required to match.

“Best in Class” States in I/DD Services (Costs & Benefits)

Reagor, C. (2018, September 30). New Phoenix apartments open for adults with autism. *The Arizona Republic*. <https://www.azcentral.com/story/money/real-estate/catherine-reagor/2018/09/30/phoenix-apartments-called-first-place-adults-autism-opens/1421650002/>

This article talks about the new apartment complex opened up in Phoenix. It details all the new features introduced and the community based system implemented for adults with autism.

Tanis, E.S., Lulinski, A. & Wu, J., Braddock, D. & Hemp, R. (2020). *IDD Comparison Chart: 2017 Home and Community Based (HCBS) Waiver Federal-State Spending Per Capita (Citizen of General Population [Data set]*. Regents of the University of Colorado. <https://stateofthestates.org/create-idd-chart/idd-comparison-chart>

This chart provides a detailed comparison of the total fiscal spending for each of the states towards I/DD services.

United Cerebral Palsy & Ancor Foundation. (2019). *The case for inclusion 2019*. [Report]. http://mediad.publicbroadcasting.net/p/wusf/files/201901/UCP_Case_for_Inclusion_Report_2019_Final_Single_Page.pdf

This report reviews how well state Medicaid programs serve individuals with intellectual and developmental disabilities (I/DD) and their families. This report ranks each individual state's performance with inclusion, support and empowerment for people with I/DD in the United States.

Average Compensation for Caregivers to the I/DD Community (State-by-State)

AARP. (2021, October 15). Can I get paid to be a caregiver for a family member? *American Association of Retired Persons*. <https://www.aarp.org/caregiving/financial-legal/info-2017/you-can-get-paid-as-a-family-caregiver.html?intcmp=AE-CAR-CAH-BB-LL>

This newspaper article was written and sponsored by AARP. AARP is an interest group that tends to the needs of elderly americans. The article explains the ins and outs of being a caregiver to a loved one and potentially receiving compensation from well known governmental services such as medicaid or U.S. military veteran help.

AARP. (2020). Long-Term Services and Supports State Scorecard 2020 Edition: Appendices [White paper].

<http://www.longtermscorecard.org/~media/Microsite/Files/2020/Full%20Appendices.pdf>

Long Term Scorecard is a part of the American Association of Retired Persons (AARP). They include a long-term services and supports (LTSS) state scorecard for 2020 that includes an overall ranking matrix heat map portraying the LTSS effectiveness for each state.

Bureau of Labor Statistics. (2021, September 8). Home health and personal care aides.

Occupational Outlook Handbook, U.S. Department of Labor.

<https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm#tab-1>

This governmental website offered valuable information regarding the job description of caregivers within the United States. The occupational handbook provided several key facts for caregivers.

Family Caregiver Alliance. (2021). *Caregiver Statistics: Demographics*.

<https://www.caregiver.org/resource/caregiver-statistics-demographics/>

This website was written and sponsored by Family Caregiver Alliance. FCA is a highly reputable site that offers in-depth information regarding caregiver statistics within the United States.

Medicaid. (n.d.). Estate Recovery. *Centers for Medicare & Medicaid Services*. Retrieved

November 28, 2021, from <https://www.medicaid.gov/medicaid/eligibility/estate-recovery/index.html>

This federal source provides an accurate description of the Estate Recovery Act covered by state Medicaid programs. Medicaid's website stipulates the requirements for dependents of Medicaid enrollees to be eligible for the act.

National Alliance for Caregiving & AARP. (2020, May). *Caregiving in the U.S.* [Report].

<https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

This governmental website offered valuable information regarding the job description of caregivers within the United States.

This research report was written by NAC and AARP. It provided the most recent report on caregivers within the United States. The report was published in 2020.

Paying for Senior Care. (2021). *Can I Be Paid for My Aging Loved One?*.

www.payingforseniorcare.com/caregiver

This online assessment allows I/DD caregivers to determine compensation from federal funds. The source allowed us to discover that a family caregiver may not be paid in Oklahoma and directed us to the Medicaid Estate Recovery Act.

Paying for Senior Care. (2021). *Medicaid Caregiver Child Exemption for Home Transfers*. <https://www.payingforseniorcare.com/medicaid/caregiver-child-exemption>

This source provides an in-depth review of Medicaid Caregiver Child Exemption. Paying for Senior Care is a hub of information on financial resources available to seniors, which can include members of the I/DD community.

Ziprecruiter, Inc. (n.d.). *What is the average caregiver salary by state in 2021?*. Retrieved November 8, 2021, from <https://www.ziprecruiter.com/Salaries/What-Is-the-Average-Caregiver-Salary-by-State>.

Ziprecruiter is a well-known recruiting website that helps thousands of people find jobs each year. It provides the most recent jobs available in a specific area. It has proven to be a reliable search tool for many. This website reveals the average caregiver salary by state within the United States. It also provides the highest paying states that offer jobs for developmental disability caregivers.

Technology Utilized by Other States to Link Caregivers and Funding to Support the I/DD Community

Forman. (2021, July 1). A very joyful moment: Medicaid expansion takes effect in Oklahoma. *The Oklahoman*.
<https://www.oklahoman.com/story/news/2021/07/01/oklahoma-expands-medicaid-after-years-debate-becoming-37th-expansion-state/7786089002/>

This newspaper article from *the Oklahoman* explains the \$164 million allocated to Oklahoma's Medicaid expansion from July 1, 2021 because of COVID-19.

I/DD State Expenditures on Average and Comparatively vs. Oklahoma (Overall & Per Capita)

Murray, C., Tourtellotte, A., Lipson, D., & Wysocki, A. (2021, January). Table C.9. Total ICF/IID expenditures by state, FY 2016–2018 [Table]. *Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018*.

Mathematica. <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf>

https://stateofthestates.org/wp-content/uploads/2020/03/SLN-Data-Brief_3.26.2020.pdf

This table is found in a report regarding Medicaid long term services. The table shows the states' expenditures for I/DD services from FY 2016 to FY 2018.

Tanis, E. (2020, March). Data Brief 2020 (2): Family Support in the United States. *The State of the States in Intellectual and Developmental Disabilities*. https://stateofthestates.org/wp-content/uploads/2020/03/SLN-Data-Brief_3.26.2020.pdf

This website is a project funded by the Administration on Disabilities, the U.S. Health Department and Human Services, and the University of Colorado School of Medicine, Department of Psychiatry. It includes many data briefs, reports, and other findings about I/DD services & expenditures as related to the United States. This data brief reports on spending in the U.S. for family support services as a total part of I/DD spending. It provides insight on the lack of funding for family support and how it needs to be increased.