Table of Contents

Table of Figures

Acknowledgements

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Introduction

The Missouri Developmental Disabilities Council (MODDC) identified the need to better understand the health needs and disparities in health between people with intellectual and developmental disabilities (IDD) and the general population in Missouri. MODDC contracted with the University of Missouri-Kansas City's Institute for Human Development (UMKC-IHD) to conduct a comprehensive review of data exploring health disparities in Missouri. UMKC-IHD partnered with the UMKC Department of Biomedical and Health Informatics and Children's Mercy Research Institute for this project.

This review of data explores health disparities for people with intellectual and developmental disabilities (IDD) compared to the general population. An emphasis on health status, behavioral health, health outcomes and morbidity across the lifespan were a key focus. Findings from this work also help the exploration of the gap in data on healthcare in Missouri for people with IDD.

Approach

To complete this project, the project team engaged in various activities explained in depth below. The project team formed an advisory council at the beginning of this work to help inform the project. Next, the project team identified several data sources to address the goals of the work. All data sources were analyzed to provide insights into the health of Missourians.

Advisory Council

The project team placed heavy emphasis on collaboration throughout the duration of this work. More importantly, the project team wanted to ensure that people in the community could influence the work by prioritizing and sharing the current needs of the IDD community. In the first quarter of the project, an advisory council was formed consisting of statewide partners focusing on health for people with IDD. The advisory council consisted of researchers, policy makers, and people with lived experience (people with disabilities and family members). The commitment to be on the advisory council included: 1) being a council member for the duration of the project, 2) attending meetings every quarter, and 3) providing expertise on IDD and/or data used in this project.

A total of 17 people were initially recruited for the advisory council, eleven became reoccurring members. The majority of the council consisted of professionals in the disability field with expertise in research and data. Two members with lived experience as family members for a person

with IDD were also part of the advisory council. All members provided feedback and highlighted the importance of sharing the projects' findings. Representation from organizations known to work for the enhancement of people with IDD represented on the project included: the IDDRC (the Intellectual and Developmental Disability Resource Center), the Department of Mental Health-Division of Developmental Disabilities, and Children's Mercy Research Institute, to name a few.

At the beginning of the project, the team presented the aims of the project to the advisory council; feedback was provided on resources as well as unique perspectives that could guide the work. The meetings were quarterly but email exchanges were also sent to continue conversations between each meeting. The meetings presented an opportunity to network with professionals in different disciplines. For example, in one meeting, council members shared the work that is done in their area of focus and were able to connect about potential collaboration on various projects. The project team valued the continuous engagement and follow-up from the council members.

Data

Several data sources were identified and used for analysis in this project. The project team had access to 2022 consumer demographics data provided by the Missouri Department of Mental Health – Division of Developmental Disabilities (DDD). This data included individuals currently on a Medicaid waiver. Given the data that was provided, the project team identified three variables (age, race, and ethnicity) to help understand different characteristics of people receiving Medicaid in Missouri. Each variable was re-coded, and frequencies and percentages were calculated for each category. Following this analysis, the project team compared the data to the US census data to help understand what this population looked like compared to the population estimates of Missourians. We chose these three variables due to a direct comparison being available in the census data.

The project team also used the following sources for additional information: MO census data (gathered from the American Community Survey), the 2021 Comprehensive Review and Analysis by UMKC-IHD, the National Core Indicators Family Surveys, Centers for Medicare and Medicaid Services (CMS), and the Behavioral Risk Surveillance System (BRFSS) data. All data cleaning, re-coding, and analyses were conducted using Microsoft Excel in combination with SAS 9.4. Data is displayed using Microsoft tools.

Findings

There is no single dataset that contains all the information that is relevant for this work. As such, the project team identified different datasets and resources to help explain the disparities that might exist between people with IDD and the general population in Missouri.

Department of Mental Health-Division of Developmental Disabilities (DDD) data

While all people with IDD are not on a Medicaid waiver, this group of individuals is important to understand. When looking at this group, the project team compared some demographics to census data to understand what the DDD demographics were in comparison to state estimates.

When looking at age, the project team compared age groups according to the categories used in the NCI surveys as these are widely used surveys across the country to understand the health of people with IDD. Table 1 displays the frequencies of DDD data for each age group in addition to the MO census estimates. A calculated percentage difference is also included with a plus sign (+) indicating when the DDD data has a percent value more than the census and a minus sign (-) indicating when the DDD data has a percent value less than the census. For example, for the under 18 years age group, the DDD data frequency was 33.39% of the population while the MO census estimates for that same age group were 22.4%. Therefore, the % difference between the two was a positive 11%. The age with the lowest difference is the 35-44 years category. The DDD data frequency had 2% less than the census estimates.

Table 1. DDD Data vs. 2021 MO Census Estimates: Age

	DDD Data Frequencies		MO Census Estimates (2021)		
Age	**N**	**%**	**N**	**%**	**% difference**
Under 18 years	14,381	33.39%	1,383,537	22.4%	11% +
18 to 24 years	7,873	18.28%	558,016	9.0%	9% +
25 – 34 years	7,962	18.49%	800,642	13.0%	5% +
35 – 44 years	4,744	11.01%	796,300	12.9%	2% -
45 – 54 years	3,262	7.57%	717,744	11.6%	4% -
55 – 64 years	2,916	6.77%	827,180	13.4%	7% -
65 – 74 years	1,398	3.25%	652,869	10.6%	7% -
75 years and older	367	0.85%	431,899	7.0%	6% -
Missing	166	0.39%	-	-	-
Total	**43,069**	**100%**	**6,168,187**	**100.0%**	**-**

The next variable analyzed was race. Race categories were calculated for DDD data and compared with MO census and shown in Table 2. Similar to the above table, a plus sign (+) indicates that the DDD data has a percent value more than the census, while a minus sigh (-) indicates that the DDD data has a percent value less than the census. For example, the census estimate for white individuals is 77.43% of Missouri residents while the DDD reports 65.35% of individuals identifying white as their race; this is a 12.08% difference. The DDD category for two or more races in also lower than the census estimates for this category with a difference of 5.84%. Conclusions cannot be made from this data as 19.65% of the DDD data is unknown or missing. Due to this, any analysis using race as a variable of interest will yield little useful results in our study.

Table 2. DDD Data vs 2021 MO Census Estimates: Race

	DDD Data Race Frequencies		MO Census Estimates (2021)		
Race	**N**	**%**	**N**	**%**	**% difference**
White	28147	65.35%	4775960	77.43%	12.08% -
Black or African American	5253	12.20%	666815	10.81%	1.39% +
Two or more races	760	1.76%	468701	7.60%	5.84% -
Asian	354	0.82%	124164	2.01%	1.19% -
American Indian or Alaska Native	72	0.17%	22046	0.36%	0.19% -
Native Hawaiian or Pacific Islander	14	0.03%	7157	0.12%	0.09% -
Other	8	0.02%	103344	1.68%	1.66% -
Unknown	8461	19.65%	-	-	-
Total	**43069**	**100%**	**6168187**	**100%**	

The final variable of DDD data that was compared to MO census estimates is ethnicity which looks at people who identify as Hispanic or Latino and people who do not identify this way. The project team created the ethnicity variable from DDD state 'race' categories as race included both racial and ethnic categories. Table 3 shows the ethnicity breakdown of people in the DDD data compared to the census estimates. The minus sign (-) in the % difference column indicates that the DDD data has a percent value less than the census estimates. There were some unknown individuals in DDD data (4.6%). The frequency of people who identified as Hispanic of Latino was 1.7% in the DDD data compared to an estimate of 4.56% for the Missouri population according to the census.

Table 3. DDD Data vs 2021 MO Census Estimates: Ethnicity

	DDD Data Ethnicity Frequencies		MO Census Estimates (2021)		
Ethnicity	**N**	**%**	**N**	**%**	**% difference**
Hispanic or Latino	719	1.7%	281445	4.56%	2.86% -
Not Hispanic or Latino	40386	93.8%	5886742	95.44%	1.64% -
Unknown	1964	4.6%	-	-	
Total	**43069**	**100%**	**6168187**	**100%**	

The health status of people with IDD and those without in Missouri are affected by several key factors. Below are some key factors found in the data that highlight the current health status and need in Missouri as well as highlighting the disparities between the two groups. This data comes from multiple sources.

Transportation

Transportation can help increase access to healthcare and provide the ability to participate in community activities that could enhance health outcomes. Without transportation, people have difficulty being able to engage in their chosen community. This difficulty is especially true for families who live in rural areas. The 2021 Comprehensive Review and Analysis (CRA) by UMKC-IHD emphasizes this gap. The CRA survey results show that 31% of the 539 respondents mentioned that the lack of transportation made it difficult for them to find and keep employment in addition to making it difficult to engaged in desired daily activities (Barton & Swinford, 2021). According to the 2020-2021 NCI Adult Family Survey report, 55% of respondents receive transportation services, but 15% still cited that a lack of transportation makes it hard to take part in activities in the community. Although not apparent, transportation is directly related to health as it provides avenues for individuals to participate in their community; this has the potential for individuals to be healthier and have a better quality of life.

Transportation is a social determinant of health; access to reliable and safe transportation can increase access to healthcare.

Furthermore, transportation directly provides some insights as to the individual's ability to go to scheduled appointments or non-emergency visits. Readily available transportation allows the reduced need for emergency services as folks can easily go to clinics for walk-in services prior to a critical health issue. In other words, with access to transportation, individuals are able to utilize non-emergency and preventive services instead of waiting for medical emergencies that require an ambulance or other emergency response transportation.

Insurance

Insurance coverage is another key health indicator. According to the 2022 American Community Survey (ACS), about 1,143,690 (17%) of Missouri residents have a disability. The census, which uses data collected from the ACS, does not differentiate IDD within the disability category. In other words, "disability" in the below tables is not exclusive to IDD.

Table 4 shows the percentage of people with and without a disability by insurance type (private health insurance, public health insurance, and no insurance). Table 5 the same data displayed a different way. In this table, we looked at disability status compared to health insurance. It is important to look at these tables together to best understand insurance and disability status in this population. Of all individuals who have private insurance, 89% do not have a disability. On the other hand, of all individuals who have public insurance, 69% do not have a disability. However, most individuals with a disability have public health insurance (56%) and more than a third have private insurance (39%). People with disabilities may qualify for public health insurance more than people without disabilities which may be an explanation for this difference.

Table 4. Health insurance by disability status

	With a disability:	%	Without disability:	%
Private Health Insurance	440,375	38.50%	3,734,431	66.30%
Public Health Insurance	638,968	55.87%	1,445,688	25.67%
No Health Insurance	64,347	5.63%	452,194	8.03%
TOTAL	**1,143,690**	**100.00%**	**5,632,313**	**100.00%**

Table 5. Disability status and health insurance

	Private Health Insurance	%	Public Health Insurance	%	No Health Insurance	%
With Disability	440,375	10.55%	638,968	30.65%	64,347	12.46%
Without Disability	3,734,431	89.45%	1,445,688	69.35%	452,194	87.54%
TOTAL	**4,174,806**	**100.00%**	**2,084,656**	**100.00%**	**516,541**	**100.00%**

Out of those with a disability, about 6% do not have insurance, while about 8% of those without a disability do not have insurance. The lower rates of uninsured people could be attributed to the recent Medicaid expansion in Missouri. According to the Missouri Foundation for Health, there has been a 3% increase in enrollment for people with disabilities and a 15% increase for all enrollees (Centers for Medicare and Medicaid Services, 2021).

Despite higher rates of insurance enrollment, individuals with IDD and families have identified difficulties finding providers who accept insurance. In addition, the listening sessions conducted in the CRA highlights individuals identifying that insurance coverages have become more restrictive and have increased deductibles and copays (Barton and Swinford, 2021).

Cost with Medicaid

Again, while we are aware that not all people with IDD have Medicaid, we know that the Medicaid population includes many people with IDD. Because of this, we wanted to highlight the disparities that exist within this population when it comes to cost for treatment. Cost can oftentimes differ individuals from seeking treatment. The tables below show the minimum and maximum costs of visits for patients with Medicaid in each of Missouri's regions. Each of the regions are grouped according to the groups set by the Department of Mental Health's Regional Offices: Northeast, Northwest, Central, Southeast, and Southwest.

It is important to note that this dataset, from CMS, does not differentiate between people with and without a disability. This CMS dataset was last updated with 2022 data. In addition, the data does not mention what the exact costs of a procedure code are or how many times the code appears in the population. This does not include data from private insurance providers.

Table 6 shows the preventive medicine visits Medicaid pricing for new patients by region and Table 7 shows the cost of preventive medicine Medicaid copays for new patients by region. For all regions, new patients had a minimum pricing of $54.20 while the maximum pricing slightly varied per region. For individuals living in Central, Southeast, and Southwest Missouri, the pricing was at most $167.18. For those living in Northeast and Norwest Missouri, the price was slightly higher at $176.78 and $175.25 respectively.

Table 6. Preventative Medicine Visits: Medicaid Pricing for New Patients

Region	min	max	mode
Central	$54.20	$167.18	$84.04
NE	$54.20	$176.78	$89.52
NW	$54.20	$175.25	$84.04
SE	$54.20	$167.18	$84.04
SW	$54.20	$167.18	$84.04

For all regions, new patients had a copay minimum of $13.55. The max payment varied per region. Individuals from Central, Southeast, and Southwest Missouri paid a max of $41.79 while those in the Northeast and Northwest paid $44.19 and $43.81 respectively. Most often, individuals paid about $21 - $22 as their copay for each visit.

Furthermore, the most common procedure code for new patients visiting physicians is 99203. According to CMS, this procedure code refers to "office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and low level of medical decision making. When using time for code selection, 30-44 minutes of total time is spent on the date of the encounter."

Table 7. Preventative Medicine Visits: Medicaid Copay for New Patients

Region	Min	Max	Mode
Central	$13.55	$41.79	$21.01
NE	$13.55	$44.19	$22.38
NW	$13.55	$43.81	$21.01
SE	$13.55	$41.79	$21.01
SW	$13.55	$41.79	$21.01

The most common procedure code for established patients visiting physicians is 99213. According to CMS, this procedure code refers to "office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and low level of medical decision making. When using time for code selection, 20-29 minutes of total time is spent on the date of the encounter." Table 8 shows the preventative medicine cost by region whereas table 9 shows the Medicaid copay for established patients.

Table 8. Preventative Medicine Visits: Medicaid Pricing for Established Patients

Region	Min	Max	Mode
Central	$16.43	$136.29	$68.33
NE	$16.43	$144.40	$72.82
NW	$16.43	$143.10	$68.33
SE	$16.43	$136.29	$68.33
SW	$16.43	$136.29	$68.33

Table 9. Preventative Medicine Visits: Medicaid Copay for Established Patients

Region	Min	Max	Mode
Central	$4.11	$34.07	$17.08
NE	$4.11	$36.10	$18.21
NW	$4.11	$35.77	$17.08
SE	$4.11	$34.07	$17.08
SW	$4.11	$34.07	$17.08

Another important cost to look at with this population is the cost of psychiatry visits as mental health care is important for everyone, especially people with IDD. By continuing to use the CMS provider data, we looked at the cost for new and established patients for the most common procedure code.

As seen in Table 10, for all regions, the minimum price for a new patient psychiatry visit is $54.20. The maximum price varied per region. For those living in central, Southeast, and Southwest Missouri, their max price was $167.18. For folks in the Northeast and Northwest regions, their max prices were $176.78 and 175.25 respectively. The most common price was $167.18, which is also the max price of most regions. The exception is $178.77 in the Northeast region.

Table 10. Psychiatry Visits: Medicaid Pricing for New Patients

Region	Min	Max	Mode
Central	$54.20	$167.18	$167.18
NE	$54.20	$176.78	$176.77
NW	$54.20	$175.25	$167.18
SE	$54.20	$167.18	$167.18
SW	$54.20	$167.18	$167.18

For all regions, the minimum copay amount is $13.55. This is shown in Table 11. The maximum copayment varies by region. The copayment of Central and the Southern regions are $41.79. On the other hand, those in the Northeast and Northwest Regions pay a max of $44.19 and $43.81 respectively. The most common copayment was $41.79 except for the Northeast region which is $44.19. The numbers suggest that new patients in the Northeast often pay the max amount of copay per visit in psychiatric offices.

Table 11. Psychiatry Visits: Copay for New Patients

Region	Min	Max	Mode
Central	$13.55	$41.79	$41.79
NE	$13.55	$44.19	$44.19
NW	$13.55	$43.81	$41.79
SE	$13.55	$41.79	$41.79
SW	$13.55	$41.79	$41.79

Moreover, the most common procedure code for new patients visiting psychiatric offices is 99205. According to CMS, this procedure code refers to "office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and high level of medical decision making. When using time for code selection, 60-74 minutes of total time is spent on the date of the encounter."

Table 12. Psychiatry Visits: Medicaid Pricing for Established Patients

Region	Min	Max	Mode
Central	$16.43	$136.29	$68.33
NE	$16.43	$144.40	$72.82
NW	$16.43	$143.10	$68.33
SE	$16.43	$136.29	$68.33
SW	$16.43	$136.29	$41.79

As seen in Table 12, for all regions, the minimum pricing for established patients is $16.43. The max pricing for Central and Southern regions of Missouri is $136.29. The max pricing for the Northeast and Northwest is $144.40 and $143.10 respectively. The most common price in each region varies. For Central, Northwest, and Southeast regions, the most common price is $68.33. For Southwest, it is $41.79, while for Northeast it is $72.82.

In Table 13, we show the minimum copayment at $4.11. The max copayment for the Central and Southern regions of Missouri is $34.07. For the Northeast and Northwest regions, their max copayments are $36.10 and $35.77 respectively. The most common copayments is $17.08 for all regions except the Northeast region, which has $18.21 as their most common copayment.

Table 13. Psychiatry Visits: Copay for Established Patients

Region	Min	Max	Mode
Central	$4.11	$34.07	$17.08
NE	$4.11	$36.10	$18.21
NW	$4.11	$35.77	$17.08
SE	$4.11	$34.07	$17.08
SW	$4.11	$34.07	$17.08

Like the established patients visiting physicians' offices, the most common procedure code for established patients visiting psychiatric offices is 99213. According to CMS, this procedure code refers to "office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and low level of medical decision making. When using time for code selection, 20-29 minutes of total time is spent on the date of the encounter."

As stated earlier, though Medicaid has helped create more affordable services, many families struggle to find providers who accept Medicaid insurance or who even offers this service (Barton & Swinford, 2021).

Behavioral Risk Factor Surveillance System

The BRFSS is a nation-wide system that collects health-related risk behaviors, use of preventive services, and chronic conditions through telephone surveys. This system is run by the Centers for Disease Control and Prevention (CDC) and administered throughout the country. The research

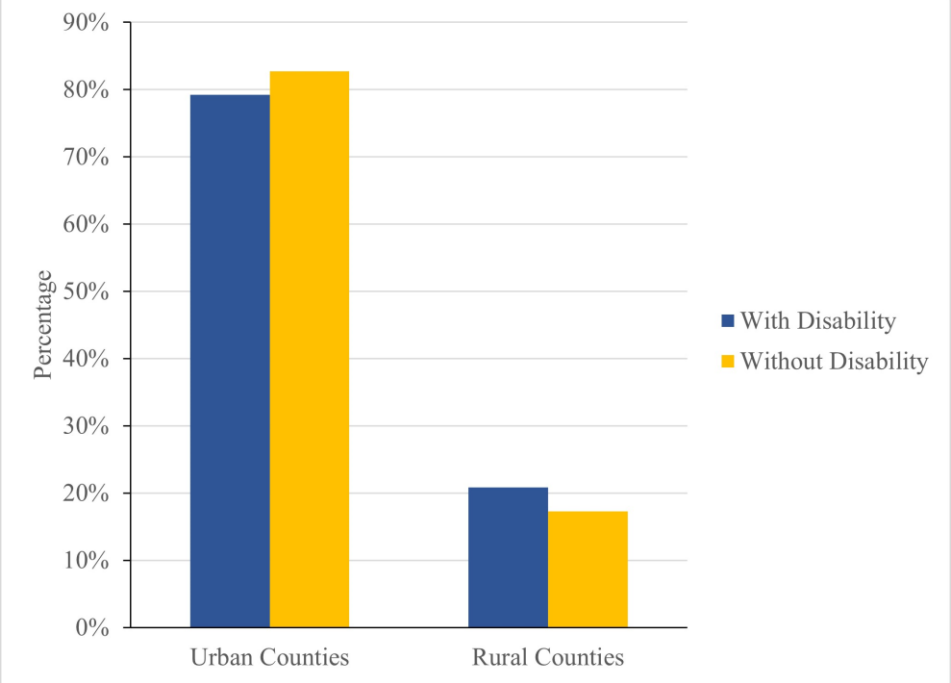
team analyzed data from the 2022 BRFSS data to understand the health of Missourians.

Like many other nationwide surveys, BRFSS does not have a category exclusive to people with IDD. Instead, the project team created a "disability" variable if respondents answered "yes" to at least one of the disability questions around cognitive disability, hearing disability, mobility disability, vision disability, self-care disability, and independent living disability.

Data is displayed for people with and without disabilities in Missouri who answered the questions deemed relevant to this study. Percentages will be compared to highlight any differences in the population. 35.6% of the respondents fell in the category of a person with a disability. While this is higher than state and national numbers for people with disabilities, the BRFSS uses a weighting schema to reduce bias that could be caused to unequal probability of a certain segment of the population responding to the survey.

To begin, some demographic characteristics were looked at in this population. Rural vs urban demographics (Figure 1), biological sex (Table 15), sexuality (Table 16), race (Table 17), ethnicity (Table 18) and income (Table 19) were all compared for people with disabilities in this survey population compared to people without.

Figure 1. Urban vs Rural by Disability



In the population of people with a disability, 79.2% lived in a rural county compared to 82.7% of people without a disability. 20.8% of people with a disability lived in a rural county compared to 17.3% of people without a disability.

Table 15. Sex by Disability

	With Disability		Without Disability	
Sex	**Frequency**	**%**	**Frequency**	**%**
Male	1168	44.1%	2228	48.8%
Female	1480	55.9%	2334	51.2%
Total	**2648**	**100.0%**	**4562**	**100.0%**

When it comes to biological sex, the population of people without a disability was closer to equal numbers with male making up 48.8% of the population and females making up 51.2% of the population. For people with a disability, males were lower at 44.1% of the population.

Table 16. Sexuality by Disability

	With Disability		Without Disability	
Transgender	**Frequency**	**%**	**Frequency**	**%**
Yes, transgender, male to female	5	0.2%	7	0.2%
Yes, transgender, female to male	6	0.2%	5	0.1%
Yes, transgender, gender nonconforming	14	0.5%	7	0.2%
No	2500	98.0%	4271	98.5%
Don't know/not sure	7	0.3%	7	0.2%
Refused	18	0.7%	41	0.9%
Total	**2550**	**100.0%**	**4338**	**100.0%**

While BRFSS does not collect data on all gender identities, it was important to highlight the question regarding transgender identity. As seen in Table 16, double the number and percent of people with a disability identify as gender non-conforming compared to those without a disability. A 2020 article conducted a study on cross-sectional datasets of over 600,000 individuals. This study found that compared to cisgender individuals, transgender and gender-diverse individuals have higher rates of autism and other neurodevelopmental diagnoses (Warrier et al., 2020). The inclusion of gender identity is important in understanding the IDD population.

Table 17. Race by Disability

	With Disability		Without Disability	
Race	**Frequency**	**%**	**Frequency**	**%**
White	2183	82.4%	3785	83.0%
Black	300	11.3%	475	10.4%
American Indian or Alaskan Native	51	1.9%	52	1.1%
Asian	16	0.6%	93	2.0%
Native Hawaiian, or other Pacific Islander	5	0.2%	7	0.2%
Multiracial	8	0.3%	12	0.3%
Don't know/Not sure	14	0.5%	19	0.4%
No race choice given	9	0.3%	12	0.3%
Refused	62	2.3%	106	2.3%
Total	**2648**	**100.0%**	**4561**	**100.0%**

Racial categories were already explored viewing DDD data, but BRFSS also reports racial categories. These comparisons are shown in Table 17. Percentages of most racial categories are similar between people with disability and people without in this dataset.

Table 18. Ethnicity by Disability

	With Disability		Without Disability	
Ethnicity	**Frequency**	**%**	**Frequency**	**%**
Hispanic, Latino/a, Spanish Origin	75	2.8%	122	2.7%
Not of Hispanic, Latino/a, Spanish Origin	2554	96.5%	4391	96.3%
Don't Know, Refused, Missing	19	0.7%	49	1.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Individuals who identify as Hispanic, Latino/a, or of Spanish origin is similar in both the disability group and the group without a disability.

Table 19. Income by Disability

	With Disability		Without Disability	
Income Range	Frequency	%	Frequency	%
Less than $15,000	351	13.3%	168	3.7%
$15,000 to < $25,000	344	13.0%	224	4.9%
$25,000 to < $35,000	272	10.3%	308	6.8%
$35,000 to < $50,000	331	12.5%	527	11.6%
$50,000 to < $100,000	526	19.9%	1310	28.7%
$100,000 to < $200,000	202	7.6%	927	20.3%
$200,000 or more	48	1.8%	257	5.6%
Don't know/not sure/ missing	574	21.7%	841	18.4%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Table 19 shows the income range of people with a disability and people without. The largest difference exists in the "less than $15,000" income bracket with 13.3% of the population with a disability compared to 3.7% of people without a disability. This is similar to trends that show people with disabilities more likely to live in poverty than their counterparts.

Health Status - BRFSS

BRFSS was used to look at health status, health outcomes and morbidity in the disability population compared to the general population. Below is some data on the health status of this group.

BRFSS asks individuals to rate their health status between "good or better health" and "fair or poor health". The majority of people without a disability rated their health "good or better" compared to only 58.8% of people with a disability; this is shown in Table 20. People with disabilities often identify with having poorer health. More tailored programs can help the health status of this population.

Table 20. Health Status by Disability

	With Disability		Without Disability	
Health Status	**Frequency**	**%**	**Frequency**	**%**
Good or Better Health	1556	58.8%	4160	91.2%
Fair or Poor Health	1075	40.6%	396	8.7%
Don't know/Not Sure or Refused/Missing	17	0.6%	6	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Smoking and alcohol consumption are also important health status indicators. Table 21 shows the smoking status of people with and without a disability with a higher percentage of people with a disability (17.3%) identifying as being a current smoker compared to those without a disability (9.3%).

Table 21. Smoking Status by Disability

	With Disability		Without Disability	
Smoking Status	**Frequency**	**%**	**Frequency**	**%**
Current smoker - now smokes every day	459	17.3%	426	9.3%
Current smoker - now smokes some days	133	5.0%	165	3.6%
Former smoker	874	33.0%	1109	24.3%
Never smoked	1139	43.0%	2805	61.5%
don't know/refused/missing	43	1.6%	57	1.2%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Table 22 shows the level of heavy alcohol consumption. Both groups showed higher levels of no heavy alcohol consumption. Compared to smoking, alcohol is not a huge concern in this population.

Table 22. Heavy Alcohol Consumption by Disability

	With Disability		Without Disability	
Heavy Alcohol Consumption?	**Frequency**	**%**	**Frequency**	**%**
No	2402	90.7%	4070	89.2%
Yes	147	5.6%	338	7.4%
Don't know, not sure, missing	99	3.7%	154	3.4%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Another indicator of health status is going to the dentist. Dental visits are important for overall health. Table 23 shows the response of the population when asked when their last dental visit was conducted. Around 50% of people with disabilities said within the past year as opposed to 67% of the population without a disability. Dental health is currently a pressing issue in the IDD community.

Table 23. Last Dental Visit by Disability

	With Disability		Without Disability	
Last Dental Visit	Frequency	%	Frequency	%
Within the past year (anytime < 12 months ago)	1380	52.1%	3060	67.1%
Within the past 2 years (1 year but < 2 years ago)	335	12.7%	527	11.6%
Within the past 5 years (2 years but < 5 years ago)	359	13.6%	429	9.4%
5 or more years ago	512	19.3%	467	10.2%
Don't know/Not sure	47	1.8%	47	1.0%
Never	13	0.5%	27	0.6%
Refused	2	0.1%	5	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Chronic Diseases – BRFSS

Several chronic diseases are reported in the BRFSS dataset. Below are several chronic diseases identified in this dataset in addition to a comparison of people with disability and those without. Table 24 shows the asthma status of respondents. 14.9% of people with a disability currently have asthma compared to 7.2% of those without a disability.

Table 24. Asthma by Disability

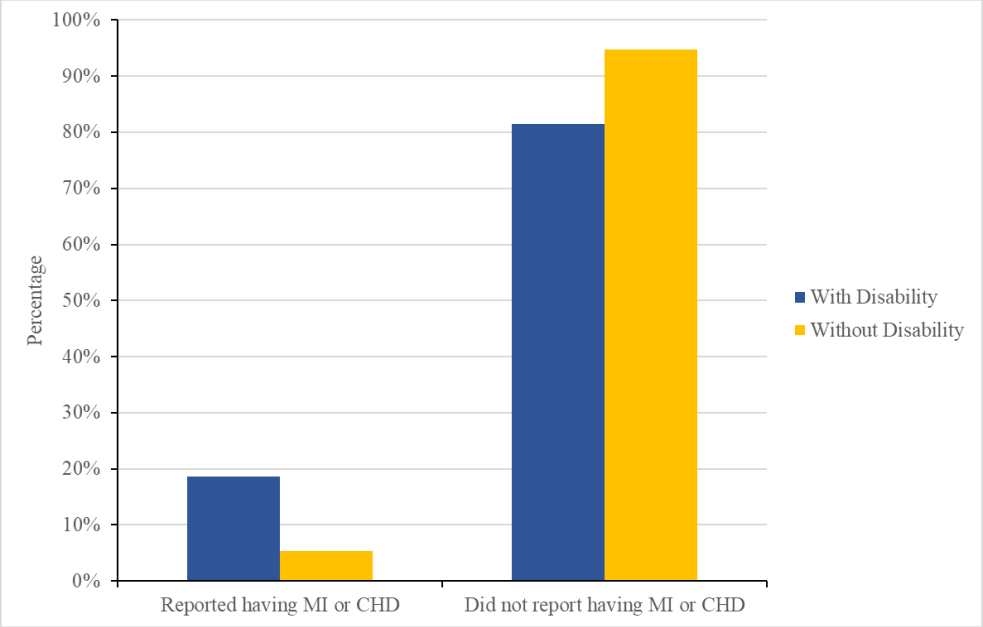
	With Disability		Without Disability	
Asthma Status	Frequency	%	Frequency	%
Current	395	14.9%	328	7.2%
Former	104	3.9%	180	3.9%
Never	2109	79.6%	4021	88.1%
Don't Know, not sure, missing	40	1.5%	33	0.7%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Table 25 shows a heart attack diagnosis for people without a disability and people with a disability. 11.8% of people with a disability reported a heart attack diagnosis compared to 3.2% of people without a disability. Figure 2 shows the percentage of people with a myocardial infarction (MI) or coronary heart disease (CHD) diagnosis. 18.6% of people with a disability reported having an MI or CHD compared to 5.3% of people without a disability. This data is showing the importance of heart health, especially for people with a disability.

Table 25. Heart Attack Diagnosis by Disability

	With Disability		Without Disability	
Heart Attack Diagnosis	**Frequency**	**%**	**Frequency**	**%**
Yes	313	11.8%	147	3.2%
No	2299	86.8%	4398	96.4%
Don't Know/Not Sure	36	1.4%	14	0.3%
Refused	0	0.0%	3	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

Figure 2. Myocardial Infarction (MI) or Coronary Heart Disease (CHD) by Disability



Another measure of heart health is stroke. Table 26 shows stroke diagnosis in both populations with people with a disability (10.3%) reporting stroke more than people without a disability (2.1%).

Table 26. Stroke Diagnosis by Disability

	With Disability		Without Disability	
Stroke Diagnosis	Frequency	%	Frequency	%
Yes	272	10.3%	98	2.1%
No	2361	89.2%	4455	97.7%
Don't Know/Not Sure	15	0.6%	6	0.1%
Refused	0	0.0%	3	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

An additional health outcome that is reported higher in the population with a disability compared to those without a disability is kidney disease at 7.5% and 2.3% respectively. Table 27 shows this data.

Table 27. Kidney Disease by Disability

	With Disability		Without Disability	
Kidney Disease	Frequency	%	Frequency	%
Yes	199	7.5%	103	2.3%
No	2429	91.7%	4442	97.4%
Don't Know/Not Sure	20	0.8%	14	0.3%
Refused	0	0.0%	3	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

There is also a disparity for arthritis diagnosis and diabetes diagnosis between the groups. Figure 3 shows arthritis diagnosis by disability with 55.4% of people with a disability reporting “yes” to arthritis compared to 24.3% of people without a disability. Table 28 also shows the higher percentage of people with a disability (21.1%) with diabetes compared to people without a disability (10.4%).

Figure 3. Arthritis by Disability

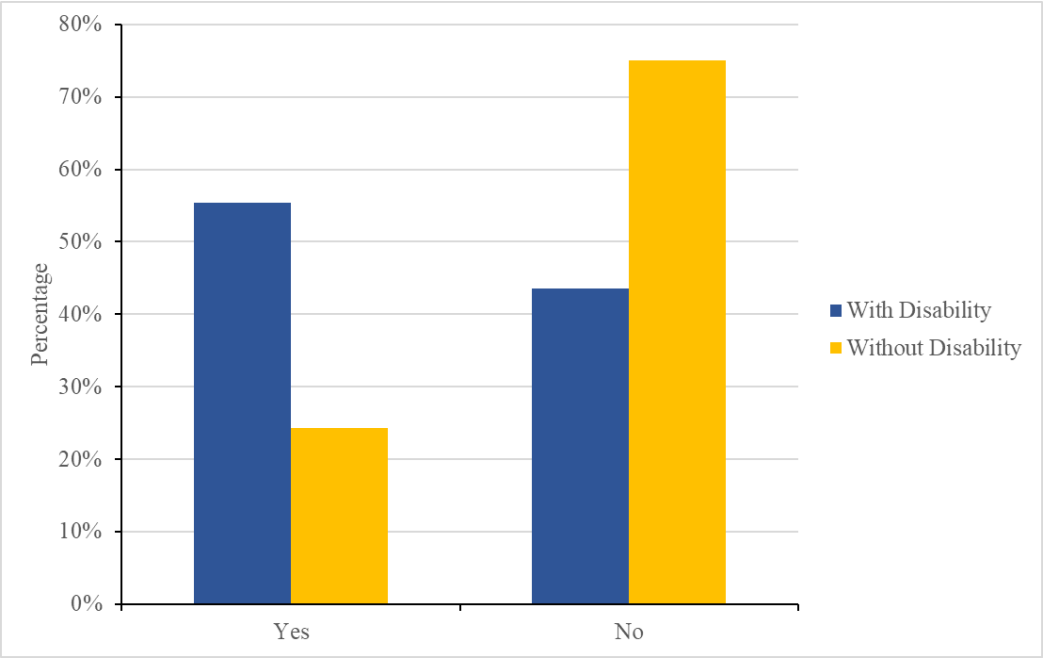


Table 28. Diabetes Diagnosis by Disability

	With Disability		Without Disability	
Diabetes Diagnosis	**Frequency**	**%**	**Frequency**	**%**
Yes	559	21.1%	464	10.2%
Yes, but told only during pregnancy	12	0.5%	32	0.7%
No	1948	73.6%	3975	87.1%
No, pre-diabetes or borderline	120	4.5%	80	1.8%
Don't know/not sure	9	0.3%	7	0.2%
Refused	0	0.0%	4	0.1%
Total	**2648**	**100.0%**	**4562**	**100.0%**

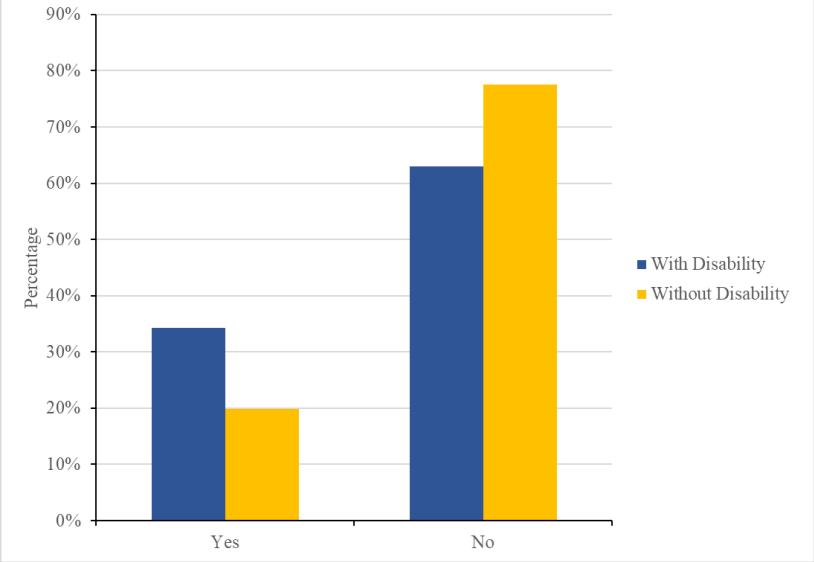
The effects of COVID-19 are currently being studied. While COVID-19 has been present throughout this study, we wanted to report the impact of this population during COVID. Table 29 shows the responses when asked if a person had received a positive COVID test with numbers being similar between the two groups. Interestingly, the long-term effects of COVID are higher for people with a disability compared to those without a disability; this can be found in Figure 4.

Respondents were asked if they had gone 3 months or longer with COVID symptoms.

Table 29. Positive COVID Test by Disability

	With Disability		Without Disability	
Positive COVID Test	Frequency	%	Frequency	%
Yes	688	26.7%	1334	30.1%
No	1824	70.8%	2885	65.1%
Test positive using at home test	52	2.0%	200	4.5%
Don't know/ not sure	11	0.4%	6	0.1%
Refused	0	0.0%	6	0.1%
Total	**2575**	**100.0%**	**4431**	**100.0%**

Figure 4. Long-term COVID Effects by Disability



Prevention-BRFSS

Another important aspect of health is access and utilization of health prevention measures and strategies. The disparities in preventive health measures between the IDD population and the general population is currently understudied. Addressing preventive health measures can increase the health and well-being of people with IDD. Several prevention questions were asked in the BRFSS data. These include mammogram tests (Table 30), pap test and recent cervical cancer screening (Figure 5), colonoscopy (Table 31), and adult flu shot/spray in the last 12 months (Table 32).

Table 30. Mammogram Test by Disability

	With Disability		Without Disability	
Mammogram Test	Frequency	%	Frequency	%
Yes	1183	80.2%	1623	69.9%
No	286	19.4%	680	29.3%
Don't know/not sure	4	0.3%	11	0.5%
Refused	2	0.1%	8	0.3%
Total	**1475**	**100.0%**	**2322**	**100.0%**

Figure 5. Pap Test and Recent Cervical Cancer Screening by Disability

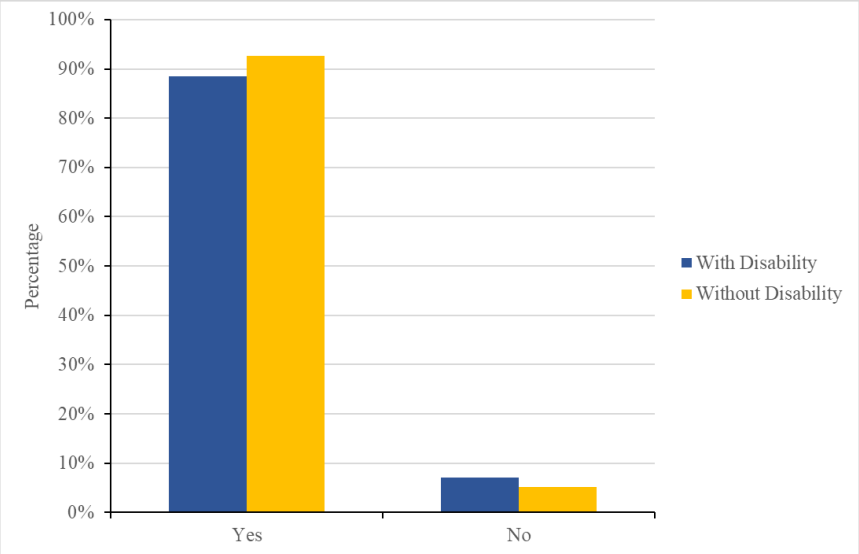
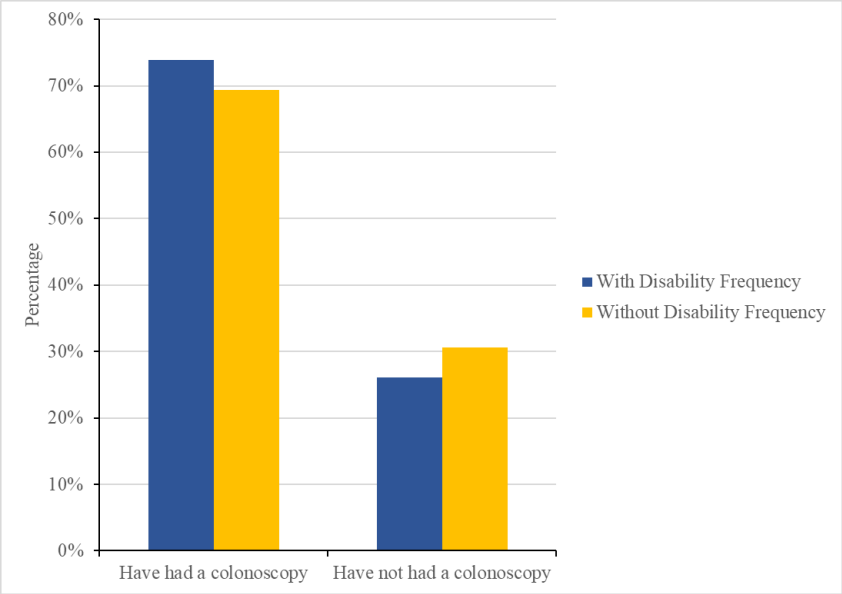


Table 31. Adult Flu Shot/Spray in the Last 12 Months by Disability

	With Disability		Without Disability	
Adult Flu Shot/Spray	Frequency	%	Frequency	%
Yes	1349	52.0%	2120	47.3%
No	1223	47.1%	2337	52.2%
Don't know/not sure	21	0.8%	16	0.4%
Refused	1	0.0%	5	0.1%
Total	**2594**	**100.0%**	**4478**	**100.0%**

A slightly higher percentage of people with a disability (52%) received a flu shot in the last 12 months compared to people without a disability (47.3%). This is also true of a colonoscopy.

Figure 6. Colonoscopy by Disability



While there are many diagnoses and screenings that can be viewed to help understand the population's health status and morbidity, by leveraging the BRFSS dataset, the project team was able to highlight some of the disparities that exist between the population with a disability compared to those without a disability.

Conclusion

This project leveraged several data sources and reports to understand the disparities between people with IDD and the general population in Missouri when it comes to health status and morbidity.

Limitations and Challenges

The following limitations and challenges were seen throughout the project period and documented throughout this work.

- One of the largest challenges to this project was the difficulty of securing different data sources due to staff turnover and data-sharing policies. For example, The project team worked with a member of the DD Council board to help secure Medicaid claims data. While fruitful, this person was the first link in a long chain people who helped access the data. After that, the data request was not acknowledged, and the project team later found

out that the person left their position and our request was not sent to the next person in the role. This wait for data took months.

- The cost of data was prohibitive from some sources. This barrier narrowed the available data sources. Data of interest ranged from $15,000-$30,000.
- Many nation-wide datasets do not exclusively categorize intellectual and developmental disabilities as a sub-group and rather have "disability" as an identifier. This over-arching "disability" category makes it difficult to make a comparison for the population of interest.
- Demographic data was missing in some of the data sources identified. This limited the possible analyses.

Recommendations

Currently, there is a nation-wide conversation led by the Administration for Community Living (ACL) on health for people with IDD. In November 2022, ACL organized a National Summit inviting people with IDD, researchers, health care providers and other stakeholders to discuss health data and health equity for people with IDD. Researchers and scholars have called for more information on how many people with IDD live in the United States, what the state of their current health is, and what are the barriers to this community's health (Administration for Community Living, 2022). ACL identifies using electronic health records and other health information as promising health data components to study health equity issues in this population (ACL, 2022). This recent call by ACL should drive future work around health for people with IDD. As previously mentioned, many nationwide datasets are not exclusive in their disability category for the IDD population. Intentional work using health records could provide insights into this population.

The IDD system in Missouri would benefit from investing in more quality and standardized data collection. With support from all state agencies, a robust data exchange and platform could lead to better understanding and quality of health for people with IDD in Missouri. Currently, much of this data is siloed and may not be similar across different counties. This investment in quality data has many short-term benefits, but the long-term benefits of this work could change the lives of many Missourians with IDD.

Sustainability and future work

This project created a community of researchers and stakeholders across Missouri who are

interested in understanding and responding to the health needs of individuals and families with IDD. This network is now connected to share upcoming research projects and findings with one another.

Additionally, the project team worked on this contract knowing that future work is needed. Given this, the project team has dedicated time to furthering the work of this grant by addressing some of the barriers that arose during the process. Given the barrier of securing recently published data that could show the health of the IDD population, and not the general population with "disabilities", the UMKC-IHD team applied for and secured funding to acquire health data to explore accessing health care disparities for people with IDD by race, ethnicity, gender, and geographical location. This work will leverage CMS data from the most recent 5-year span to identify specific preventive services including general health examinations, screenings, and gynecological services to name a few with a focus on intersectional identity in the IDD community. ***Findings from this future project will be shared with MODDC and other state agencies***.

UMKC-IHD will be leading a study using CMS data to explore preventive health care use in Medicaid recipients with IDD in the past 5 years with a focus on race, ethnicity, gender identity, and geographical location. A focus on intersectional identity in the IDD community and an exploration of identified disparities will help further the work of this project.

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