ACCESSIBLE PREVENTATIVE HEALTH CARE SERVICES AND HEALTHY LIFESTYLE RESOURCES FOR ADULTS WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES AND ADULTS WITH MOBILITY LIMITATIONS:

2022 Needs Assessment

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Executive Summary

This needs assessment was conducted as part of a five-year grant (CDC-RFA-DD21-2103) awarded to University of Missouri-Kansas City Institute for Human Development by the Centers for Disease Control and Prevention in 2021. The goal of the grant is to improve access to and participation in preventative health care services and healthy lifestyles programming among adults with intellectual/developmental disabilities (IDD) and adults with mobility limitations (ML) in Missouri. The findings of this needs assessment will guide capacity building and systems change activities over the next five years.

Landscape of Health Care and Health Programming in Missouri

Several characteristics of Missouri's health and wellness environment, such as provider shortages, cost of health care, health insurance access, and limited transportation options impact all Missourians, regardless of their disability status or disability type. However, these challenges often have a disparate impact on individuals with IDD or ML, who may already face barriers to health care related to accessibility and disability awareness. The compounding nature of these barriers make it disproportionately complicated for individuals with disabilities to engage in healthcare services and health programming.

This report outlines significant findings related to health, health care, and health programming for people with disabilities in Missouri. Data came from a variety of local, state and national sources including the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities, the Behavioral Risk Factor Surveillance System, the National Core Indicators, and the U.S. Census, among others. Additionally, qualitative and quantitative data gathered from previous statewide needs assessments were incorporated into this report.

Population with IDD: Key Findings

Health

- Nearly half (46%) of individuals with a cognitive limitation rate their health as "fair" or "poor."
- Individuals with a cognitive disability report experiencing several health conditions, such as cancer, asthma, heart disease and diabetes, at a higher rate than their non-disabled peers.
- Compared to other NCI states, Missourians with IDD report lower rates of preventative health screenings, such a colorectal exams and mammograms.

Health Care Access

- One in four Missourians with IDD cannot always see a health professional when needed; one in three cannot always go to the dentist when needed.
- Percent of NCI respondents who felt health care providers always understand patients' disability-related needs: Primary care doctor: 54%, mental health professional: 59%, dentist: 54%.

Health Behaviors and Healthy Lifestyles

- Missourians with a cognitive disability reported high rates of health risk factors, such as binge drinking, physical inactivity, and smoking, than their non-disabled peers.
- About a third of Missourians with an IDD or their family members reported having unmet needs around parks and recreation activities and fitness programs.

Population with Mobility Limitation: Key Findings

Health

- Nearly 60% of individuals with a mobility limitation rate their health as “fair” or “poor.”
- Missourians with a mobility disability report experiencing several health conditions (such as COPD, diabetes, high blood pressure, heart disease, and stroke) at a higher rate than both their non-disabled peers and the cognitive disability population.
- Compared to adults without a disability, Missourians with a mobility disability report lower rates of recommended preventative health screenings, such as mammograms and cervical cancer screenings.

Health Care Access

- In 2019, nearly 20% of individuals with a mobility limitation in Missouri had not had a routine check-up in the past 12 months.
- Nearly 18% of Missourians with a mobility limitation do not have a personal doctor.

Health Behaviors and Healthy Lifestyles

- Missourians with a mobility disability report higher rates of health risk factors, such as being overweight, being inactive, smoking, than their non-disabled peers.

Primary Barriers to Preventative Health Services and Health Promotion Programming for People with IDD and People with ML

- Lack of health care providers trained on providing accessible health care.
- Cost of medical care and health promotion activities.
- Lack of accessible, affordable, and reliable modes of transportation.
- Little strategic marketing, outreach or promotion of inclusive programming.
- Dearth of accessible health-related facilities and recreational activities.
- Scarcity of accessible services, health care, and recreational activities in rural areas.

Introduction

In 2021, Missouri was awarded the *Improving the Health of People with Mobility Limitations and Intellectual/Developmental Disabilities through State-based Public Health Programs* (CDC-RFA-DD21-2103) grant by the Centers for Disease Control and Prevention. This funding supports the continued work of the Missouri Disability and Health Collaborative by expanding the Collaborative's efforts to increase accessibility among health care providers and health promotion programs in Missouri in reach and scope.

The purpose of this needs assessment is to identify gaps in information, resources, and barriers to engagement with preventative health care services and health promotion programs among adults with intellectual and developmental disabilities (IDD) and adults with mobility limitations (ML). This report provides a snapshot of the disparities that exist around disease prevalence, access to health care services and health promotion programming in Missouri's populations with IDD and/or ML, and highlights opportunities to better meet the needs of these communities. The goal for this needs assessment is to increase knowledge about unmet preventative health care and health promotion needs for Missourians with IDD and/or ML and inform a set of action steps to address those needs.

This report defines IDD as "conditions that occur at an early age and that have a lifelong effect on an individual's learning, thinking, understanding, or reasoning, and/or emotional and physical development." Mobility limitation refers to "a reduced capacity to use the legs or arms without assistance, which includes conditions of the brain, spinal cord, nerves, and muscles such as those present at birth or in early childhood or acquired over the life course."

As much as possible, this report draws on data specific to populations with IDD and mobility limitations. In cases where data were not disaggregated by disability type, data applicable to the larger disability community was reported. In interpreting this report, it is also important to note that some individuals experience both IDD and mobility limitations, and although this document is structured into two sections (one focusing on adults with IDD and one focusing on those with ML), individuals may fall into both categories. Additionally, in many cases, contextual data or general barriers to accessing health care or health promotion programming were relevant to both populations (for example, access to transportation is a challenge for many Missourians). As such, data that were not specific to one population and data that apply to both populations are presented in-depth in the first section (focused on individuals with IDD), then are referenced throughout the remainder of the report.

This paper is organized into five sections. This first section introduces the project and lays out a roadmap for the report. The second section provides an explanation of the methodology for this report, including relevant data sources. The next section provides data specific to Missouri's population with IDD, including information on disease prevalence and demographics, engagement with preventative care, health lifestyle behaviors, and barriers to engagement. As mentioned, this section also includes data relevant to the disability population as a whole and topics that are pertinent to both groups. The fourth section shares disease prevalence, demographics, and health-related information for individuals with a mobility limitation. This section also explores barriers to participating in health care services or health promotion programs specific to this population (with the understanding that many of the barriers were previously discussed). Finally, the conclusion section highlights the common barriers to accessing health services and promotion programs for people with IDD and ML and offers recommendations.

Methodology

Data for this report were gathered from a variety of sources. Existing data were compiled from national and statewide databases such as Residential Information Systems Project (RISP), National Core Indicators (NCI), Disability and Health Data System, U.S. Census Bureau, and more. Data from other relevant sources (such as Missouri's Governor's Council on Disability, Missouri Foundation for Health, and state agencies like Missouri Division of Developmental Disabilities) were also incorporated. Existing reports, needs assessments, and comprehensive reviews and analyses previously drafted by UMKC-IHD also served as important sources of information.

Data collected and analyzed in 2020-2021 from stakeholders throughout the state also provided a more in-depth and person-centered analysis of the state of services and needs in Missouri[i]. This information was gathered as part of a 2020 needs assessment conducted by UMKC-IHD with funding from the Missouri Developmental Disabilities Council (MODDC). This needs assessment included both a survey and a series of community listening sessions, and focused on systems change and capacity building related to services and supports for people with IDD in Missouri. The survey was developed with input from UMKC-IHD staff, family members of individuals with IDD, and members of MODDC. English and Spanish versions of the survey were available online and in hard copy and 623 responses were received. UMKC-IHD also hosted thirteen 90-minute virtual Listening Sessions and five individual stakeholder interviews between July and October 2020. All sessions were conducted using a semi-structured script and the research team relied on best practices in qualitative data to guide data analyses.[ii] A total of 84 people participated in a listening session or individual interview. Among all respondents, 26% were individuals with IDD, 64% were family members of individuals with IDD, and 10% identified as "other," a category that included professionals, legal guardians, caregivers, and service providers.

Missouri's Disability and Health Collaborative Steering Committee also provided valuable information for this needs assessment. In January 2022, the committee was presented with preliminary findings from the needs assessment, including a summary of the main barriers and challenges to accessing preventative health care and health promotion programs for the populations with IDD and mobility limitations. Initially, the committee was asked to provide feedback on the content in specific sections. In a February 2022 committee meeting, findings of the needs assessment were presented, and members had the opportunity to provide feedback and contribute additional thoughts on the full report. Committee members provided valuable insights that added nuance and context to the report.

The data presented below captures the landscape of health-related supports and services for individuals with IDD and mobility limitations in Missouri. However, it is important to note that these data do not represent the full range of experiences of those living with a disability. For example, the perspectives represented in this report largely represent those who are connected to some level of services and supports--these data likely do not fully represent the perspectives of individuals who are not connected to the formal service system.

Health Outcomes and Disparities among Individuals with IDD

Prevalence of IDD

Accurately estimating the prevalence of disability in a population is challenging, and there are multiple accepted measures of IDD prevalence. However, Larson et al.'s (2001) estimate of 1.58% prevalence rate in a population is one of the most widely accepted.[iii] Additional studies shared by the Office of Developmental Disabilities calculate the prevalence rate of IDD to be as low as .76%[iv] and as high as 1.7%.[v] Based on these estimations and Missouri's population of roughly 6.137 million people, there are likely between 46,641 (.76%) and 104,329 (1.7%) Missourians living with a developmental disability (Table 1). Based on the accepted prevalence of 1.58%, there are approximately 96,965 individuals in Missouri with a developmental disability.

Table 1. Estimated Prevalence of Developmental Disabilities in Missouri

Prevalence Rate	Number of People
.76% (Steinmetz, 2006)	46,641
1.58% (Larson et al. 2001)	96,965
1.7% (CDC, 1996)	104,329

According to the 2019 ACS 1-Year Estimates, approximately 6.1% of Missouri's population, or 345,053 Missourians, have a cognitive disability (operationalized as "because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions"). The percentage of Missourians with a cognitive disability is higher than the national average, where an estimated 5.2% of the U.S. population has a cognitive disability.[vi] Among adults over the age of 18, 12.4% have a cognitive disability in Missouri, compared to a national average of 11.5%.

The 2019-2020 BRFSS indicates that 13.1% of Missourians have a cognitive limitation, defined as a serious difficulty concentrating, remembering, or making decisions.

Population Demographics

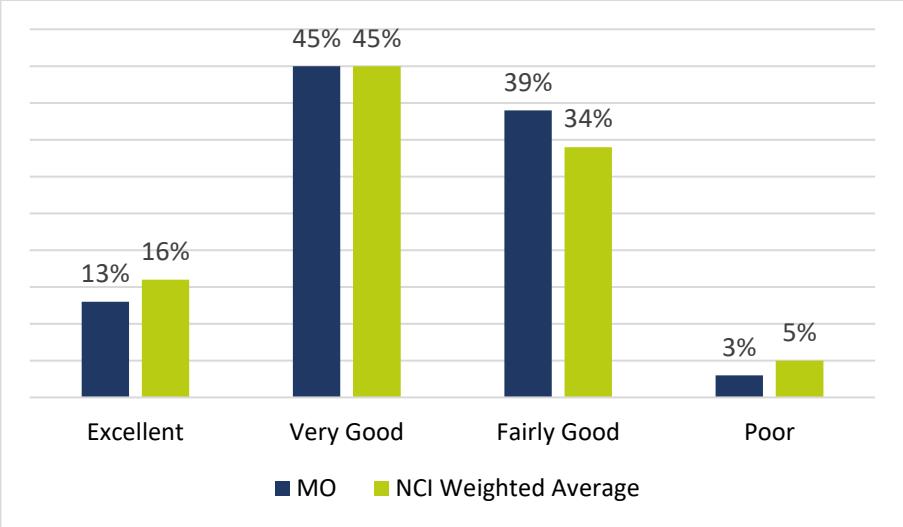
In general, individuals with a disability have lower rates of college education (14.0% for those with a disability, 31.5% for those without) than people without a disability. About 78% of Missourians over the age of 18 with a cognitive disability report having a high school education or more. This is 15% lower than the rate of those without a disability (93%). Approximately 20% of individuals with a disability have less than a high school level education, while that is the case for only about 7% of non-disabled individuals.

People with disabilities also report lower incomes than their non-disabled peers. About 59% of people without a disability earn over $50,000 a year, while only about 29% of people with a disability report that income level. About a quarter (24.6%) of Missourians with a cognitive disability earn less than $15,000 a year and 75% earn less than $50,000 annually. [vii]

Data from the 2019 BRFSS show that a higher percentage of women report cognitive limitations (14.7%) than men (11.4%), defined as having serious difficulty concentrating, remembering, or making decisions.[viii] Exploring the data along racial and ethnic group lines shows that American Indian or Alaskan Native and Hispanic populations have the highest rates of cognitive limitation (29.8% and 21.8%, respectively).

Health Demographics

Figure 1. NCI Self-Rated Health among Adults with IDD



Adults with cognitive limitations tend to be in poorer health than adults without disabilities. NCI data (which focus on adults with IDD who are receiving services) indicate that the self-reported health status of Missourians with IDD over the age of 18 is largely on par with other NCI states (Figure 1).[ix] However, when compared to other NCI states, fewer Missourians describe their health as "excellent" and more describe their health as "fairly good." Overall, about 58% of Missourians describe their health as "excellent" or "very good." Self--rated health data from the 2019 BRFSS respondents aged 18 and older indicate that nearly half (45.7%) of people with a cognitive limitation rate their health as "fair" or "poor," which is substantially higher than the 7% of non-disabled adults who rate their health similarly.[x]

As previously mentioned, those with IDD or ML have higher rates of some health conditions than those without disabilities. The NCI survey assesses the prevalence of 10 specific health conditions (and an "other" category) to gauge respondent health (Table 2). Individuals from Missouri report higher rates of oral health or dental problems and sleep apnea than the national average, and lower rates of high blood pressure, high cholesterol, and diabetes. For the other conditions, Missouri is closely aligned with other states.

Table 3 contains additional health-condition specific data, comparing prevalence rates among people with a cognitive disability, any disability, and without a disability. For all conditions, people with cognitive disabilities were more likely to experience a given health condition than those without a disability or those with any disability. The biggest disparity was with arthritis, which was experienced by 42% of the population with a cognitive ability and 17% of the non-disabled population.[xi]

Table 2. Health Conditions among Missourians with IDD and NCI States

Health Condition	MO Pop. With IDD	NCI Weighted Average
Cardiovascular Disease	8%	10%
Diabetes	13%	18%
Cancer	4%	5%
High Blood Pressure	23%	30%
High Cholesterol	25%	30%
Dysphagia	10%	10%
Pressure Ulcers	2%	2%
Alzheimer's Disease or Other Dementia	2%	2%
Oral Health or Dental Problems	18%	13%
Sleep Apnea	24%	19%
Other	25%	25%

Table 4 contains detailed information on people with IDD and health-related topics both in Missouri and across NCI states. For several indicators, Missouri had better outcomes than the national average. For example, Missourians with IDD were more likely to have had a physical exam, dental exam, and eye screening in the past year than the NCI state average. Missourians were, however, less likely to have had a recent hearing test and more likely to have never had a colorectal cancer screening than the NCI state average.[xii]

Table 3. Health Conditions among Adults with a Cognitive Disability, Any Disability, and No Disability

Condition	Cognitive Disability	Any Disability	No Disability
Ever Had Arthritis	42.4%	38.7%	17.0%
Current Asthma	17.8%	16.4%	7.8%
Ever Had Cancer (Excluding Skin Cancer)	11.9%	9.9%	5.6%
Ever Had COPD	18.9%	15.9%	3.8%
Ever Had Diabetes	14.3%	13.5%	6.3%
Ever Had a Stroke	9.0%	7.2%	1.4%
Ever Had Heart Disease	11.4%	10.9%	3.7%
Ever Had High Blood Pressure	38.9%	36.9%	23.9%
Ever Had High Cholesterol	36.8%	34.8%	26.2%

Table 4. Access to Health Care, 2018-2019

Area Reported	Missouri	Across NCI States
Have a primary care doctor	99%	98%
Are in poor health	2%	3%
Had a complete physical in the past year	92%	89%
Had a dental exam in the past year	84%	81%
Had an eye exam or vision screening in the past year	64%	58%
Had a hearing test in the past five years	41%	54%
Had a pap test in the past three years (women 21 and older)	62%	56%
Had a mammogram in the past two years (among women age 40 and over)	69%	70%
Has never had a colorectal cancer exam or screening	22%	12%
Had a flu vaccine in the past year	77%	72%
Take at least one medication for mood disorders, anxiety, behavior challenges, and/or psychotic disorders	59%	54%
Takes medication for behavior challenges and has a behavior plan	29%	54%
Exercises or does physical activity at least once a week at least 10 minutes at a time	72%	74%
BMI category - underweight	4%	5%
BMI category - within a normal weight	38%	30%
BMI category - overweight	26%	28%
BMI category - obese	32%	36%
Uses nicotine or tobacco products	7%	7%

According to Missouri's Office of Rural Health and Primary Care (ORHPC), individuals in rural areas frequently experience higher rates of chronic disease than their urban/suburban counterparts, and often have difficulty accessing needed preventative care, screenings, and other medical services.[xiii] This provides important context for understanding health access and outcomes in the state since nearly one in three Missourians live in a rural county,[xiv] and approximately 41% of individuals with IDD report living in rural areas.[xv] Understanding the complexities of rural health and health care delivery is critical to understanding the experiences of Missourians with IDD who navigate preventative health care and health programming in rural areas.

For more than 30 years, the United Health Foundation has ranked states on health-related topics and health outcomes which includes indicators related to social and economic factors, the physical environment, clinical care, behaviors, and health outcomes. In 2021, Missouri ranked #42 for health outcomes. The report identified high prevalence of frequent physical distress, low prevalence of exercise, and a high percentage of adults who avoided care due to cost as the top three challenges that contribute to Missouri's low ranking. Missouri's strengths were a high high-school graduation rate, low prevalence of high-risk HIV behaviors and low percentage of severe housing problems. Missouri's highest ranking was for physical environment (23rd) and its lowest ranking was for behaviors, a category that includes sleep health, physical activity and nutrition, sexual health, and tobacco use (41st).[xvi]

Missouri also has a particularly low rating for public health funding (#42), spending just $80 per person in 2019-2020. Alaska, the top-rated state in this category, spends $449 per person. Public health spending is important because it allows states to be proactive in improving health and preventing poor health outcomes[xvii]

Engagement with Preventative Health Care

The previous section highlighted health outcomes and health disparities among Missouri's population with IDD. This section focuses on the utilization of and engagement with preventative health care services, including primary care, dental care, mental health care, and vaccinations.

While the causes of higher rates of disease prevalence in populations with a disability are complex and multifactorial, access to health care services and health care providers is one important force. In the U.S. there are, on average, 77 primary care providers per 100,00 people. In Missouri, there are 70 per 100,000 people,[xviii] which is 22nd among all states for availability of primary care providers.[xix] Despite provider availability challenges, NCI data indicate that most respondents have a primary care doctor (99%) and have had a complete physical in the past year (92%). Over half had an eye exam or vision screening in the past year (64%). While these rates exceeded the average among NCI states, other rates remain low (e.g. about 41% of respondents from Missouri had a hearing test in the past five years, which is 13% lower than the NCI average).[xx]

Figure 2. Health care Providers' Understanding of IDD, 2019-2020

Primary care doctor always understands your family member's needs related to his/her disability:	
MO	54%
NCI States	63%
Mental health professional always understands your family member's needs related to his/her disability:	
MO	59%
NCI States	61%

About three-quarters of respondents indicated that their family member with IDD can always see health professionals when needed, which is in line with the

average for NCI states. However, this also indicates potential health care access challenges, as one in four Missourians with IDD are not always able to see a provider when they need medical care.

Satisfaction with health care providers is another important component of health care utilization. The percentage of people who feel that their health care provider understands the needs of people with IDD was lower in Missouri than the average across NCI states (54% vs. 63%, Figure 2).[xxi] Slightly more respondents felt that their family member's mental health professional always understood their disability related needs (59%) but overall, survey responses suggest that between about a third and a half of Missourians feel that the needs of their family member with IDD are not always understood by medical providers.[xxii]

Mental Health

In general, adults with disabilities report having ever experienced depression substantially more than adults without a disability (46.3% compared to 15.1%). For those with cognitive disabilities, nearly two-thirds (63.7%) reported experiencing depression at some point in their lives. This was the highest prevalence seen across disability types. Additionally, nearly 50% of adults with cognitive limitations reported having 14 or more mentally unhealthy days in the past 30 days, which was again, the highest rate among all disability types.[xxiii]

Flu Vaccinations

In 2019, 41.4% of Missourians aged 18 and over with a cognitive disability had received a flu vaccine in the past 12 months. This closely aligned to the rate of flu vaccination among the state's general population.[xxiv]

Dental Care

Clinical care data from the United Health Foundation's state rankings indicate that Missouri falls in the bottom half of states when it comes to availability of dentists (#37). Additionally, among the general population, 37% of Missourians reported that they have not visited a dentist, dental hygienist, or dental clinic within the past year, which is higher than the U.S. average (30%).[xxv]

Say the dentist always understands their family member's disability-related needs

Among the Missourians with IDD who responded to the NCI survey, 84% had seen a dentist in the past year. However, only 59% of respondents indicated that their family member always goes to the dentist when needed, which is 6% lower than the average across NCI states. Notably, 12% of respondents from Missouri "seldom or never" go to the dentist when needed.[xxvi] Additionally, only about half of respondents felt that the dentist always understood their family member's disability needs, which is lower than all other NCI states and significantly lower (10%) than the average among NCI states.[xxvii] These numbers suggest that there are meaningful barriers to accessing dental care in Missouri.

Additional Health Care Resources

In Missouri, there are several services and resources that can assist individuals with IDD in connecting with medical providers and promote the use of primary health care services. Some of these resources are outlined below.

Station MD is a service available in Missouri that connects people with IDD to trained medical professionals through telemedicine. The goal of the service is to avoid unnecessary trips to the emergency room by providing 24-hour telehealth access to emergency physicians. StationMD is available to approximately 15,000 Missourians with IDD who receive Medicaid waiver services. Unlike most health care providers, StationMD physicians are specifically trained to work with patients with IDD and care coordination services are available. Although the service largely focuses on emergency medicine rather than preventative health, it has valuable connections to primary care and a recent analysis of the program offers insight into the benefits of such a service. For example, the most common health issue reported by StationMD users was needing a medication refill or prescription order, a request that could be managed in a primary care setting.[xxviii]

ECHO Autism is a learning collaborative that serves as a source of information to educate and support clinicians on autism-related issues. The program's website also contains a repository of physicians and clinicians with ECHO Autism training. This allows individuals to identify providers who are more likely to have the familiarity and skill set to provide care to people with IDD. There are also ECHO collaboratives that focus on developmental disabilities and rural health. These groups can support medical providers serving individuals with IDD and provide them with education and resources to support their practice.

Dental LifeLine Network connects older adults, people with disabilities, and people who are medically fragile to dental providers willing to donate their time. Unfortunately, this program currently has a lengthy wait list and is only active in certain regions of the state.

Health Insurance Access

Health insurance is another important factor impacting access to all types of health care. Medicaid and Medicare benefits, which are administered by the state and federal governments respectively, have eligibility criteria that must be met in order to receive coverage. If an individual is not eligible for Medicaid/Medicare, they can purchase private insurance on the Missouri Health Insurance Marketplace, a federally facilitated Marketplace that offers health coverage in Missouri.[xxix]

Table 5. Insurance Coverage for Missourians with Disabilities

Age	With private health insurance coverage	With public health insurance coverage	No health insurance coverage
Under 19 years	41%	56%	4%
19 to 64 years	41%	47%	12%
65 years and over	36%	64%	0%
All Ages	38%	56%	6%

Across age groups, most Missourians with any disability receive their health insurance through public health insurance programs.[xxx] Among people with disabilities, adults (19-64 years old) have the highest rates of being uninsured, with 12% lacking health insurance. Table 5 contains additional information about insurance coverage by age for Missourians with a disability.

In August 2020, Missourians voted in favor of Missouri Constitutional Amendment 2, the Medicaid Expansion Initiative. The passage of this amendment expands Medicaid (MO HealthNet) services to more people and makes Missouri the 38th state to approve Medicaid expansion through the Affordable Care Act. Advocates are hopeful that expansion of the Medicaid program will allow more Missourians to access affordable health insurance coverage.

Since 2013, the Cover Missouri Coalition has been convening organizations across the state to lower the number of uninsured Missourians. The group generates awareness, assists with enrollment, provides trainings on health insurance literacy, and more. The Cover Missouri website offers health insurance related resources and assistance in four languages (English, Spanish, Bosnian, and Vietnamese).

During FY2021, the number of enrollees in MO HealthNet grew by nearly 200,000. In January 2022, there were approximately 1,190,000 Missourians enrolled in the program, and about 176,180 of those enrollees were people with disabilities.[xxxi]

Of the four populations served by MO HealthNet (older adults, people with disabilities, children, and non-disabled adults, 19-64), health care costs for people with disabilities were the highest (Table 6). The average cost for an enrollee with disabilities was $2,315 per month, which is substantially higher than any other group.[xxxii]

Table 6. Annual MO HealthNet Expenditures by Population and Individual per Month Costs, 2018

Group	Enrollees	Annual Expenditures (in millions)	Average Monthly Cost Per Enrollee (dollars)
Older Adults	80,509	$1,596	$1,652
Persons with Disabilities	156,057	$4,336	$2,315
Children	620,294	$2,595	$321
Adults (non-disabled and under 65)	119,919	$900	$676

Practice of Health Lifestyle Behaviors

While access to health care services and medical providers is important to health and well-being, many health and wellness-related decisions and behaviors occur outside of the health care system. This section focuses on healthy behaviors and engagement with and access to health promotion programming among individuals with IDD.

The Behavioral Risk Factor Surveillance System (BRFSS) data outlined in Table 7 highlights several health-related risk factors and behavior topics in populations without a disability and populations with a cognitive disability. Those with a cognitive disability were more likely to report a higher prevalence of several health risk factors, including higher rates of binge drinking in the past 30 days, being overweight, not meeting physical activity guidelines, being a current or former smoker, and being a current or former e-cigarette user.[xxxiii]

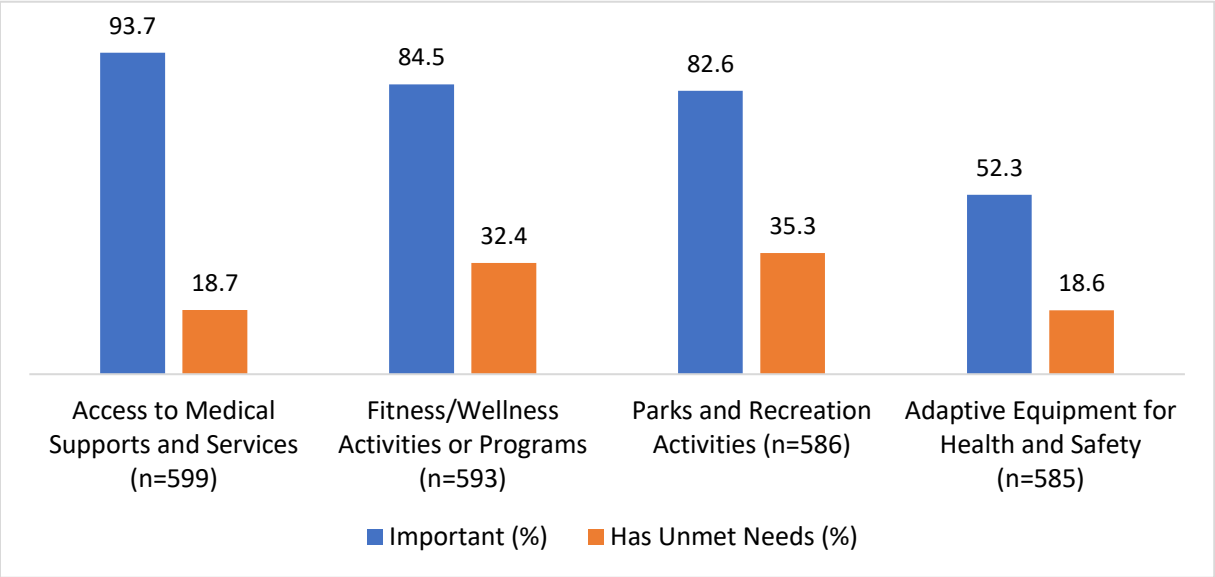
Table 7. Health Risks and Behavior Topics by Cognitive Disability, Missouri 2019

Binge Drinking in the past 30 days				
	Yes		**No**	
Cognitive Disability	21.2%		78.2%	
No Disability	18.4%		81.6%	
Body Mass Index				
	Underweight	**Normal Weight**	**Overweight**	**Obese**
Cognitive Disability	2.4%	31.4%	24.3%	41.9%
No Disability	+	24.4%	19.9%	52.8%
Aerobic Physical Activity Level				
	Sufficiently Active	**Insufficiently Active**		**Inactive**
Cognitive Disability	37.7%	19.9%		42.3%
No Disability	47.5%	24.0%		28.5%
Meets Physical Activity Guidelines				
	Meets both aerobic and muscle strengthening	**Meets aerobic only**	**Meets muscle strengthening only**	**Meets neither**
Cognitive Disability	11.3%	27.5%	10.7%	50.4%
No Disability	19.6%	28.1%	11.7%	40.7%
Smoking Status				
	Current Smoker	**Former Smoker**		**Never Smoker**
Cognitive Disability	36.4%	28.0%		35.6%
No Disability	16.0%	23.6%		60.4%
Current e-cigarette use				
	Yes		**No**	
Cognitive Disability	8.5%		91.5%	
No Disability	5.1%		94.9%	
Ever been tested for HIV				
	Yes		**No**	
Cognitive Disability	56.7%		43.3%	
No Disability	38.6%		61.4%	

+Data Suppressed. Estimates were suppressed if the standard error was greater than or equal to 30% of the estimate or if the unweighted total population was less than 50.

Findings from UMKC-IHD's Fall 2020 Statewide Needs Assessment indicate that there are several health-related domains that are important to individuals and families with IDD, but their needs in these areas are not met (Figure 3).[xxxiv] For example, more than 90% of respondents indicated that access to medical supports and services is important to them, but nearly one in five reported that they currently have unmet needs in this area. More than 80% reported that Fitness and Wellness Activities or Programs (84.5%) and Parks and Recreation activities (82.6%) are important, but more than a third indicated that their needs in these areas aren't currently being met. Finally, over half of respondents identified adaptive equipment for health and safety as an important component of their lives, but nearly 20% have unmet needs in this area.

Figure 3. Importance and Unmet Need, Health and Health Promotion Topics



Community Resources

There are several services and resources to support the health and well-being of Missourians with disabilities in healthy activities, including physical activity, general health and wellness supports, and more. Several of these services are listed below:

Accessible Sports of Greater Kansas City provides a forum to share inclusive adaptive/accessible sports activities happening in the Kansas City area. Businesses, nonprofits, community groups and other organizations that offer accessible sporting activities in the Kansas City metro area are encouraged to list their information on the website. This is a helpful source of information for people with disabilities in the Kansas City community who are looking for ways to be physically active in a supportive environment.

Disabled Athlete Sports Association provides recreational and competitive sports opportunities for children and adults with disabilities. Its offerings include a variety of recreational programs (e.g. archery, scuba diving, powerlifting), sports camps, competitive sports teams and an adaptive gym. It has services in the Columbia and St. Louis regions.

The **State of Missouri's Governor's Council on Disability** has an online Disability Portal that offers a range of resources and information on health and wellness topics for people with disabilities.

There are several **1915(c) Medicaid Waiver Programs** available through Missouri's Division of Developmental Disabilities. These waivers are designed to support Missouri's disability population in multiple life domains in the community and can expand an individual's access to health and wellness resources.[xxxv] The following waivers are available to eligible participants:

- Comprehensive Waiver
- Community Support Waiver
- Missouri Children with Developmental Disabilities (MOCDD or Sarah Jian Lopez) Waiver
- Partnership for Hope Waiver
- Autism Spectrum Disorder Waiver
- Community Support Waiver[xxxvi]

Participation in waiver programs varies considerably. Table 8 shows the number of IDD waiver participants and expenditures in Missouri in 2018. [xxxvii]

Table 8. Medicaid Section 1915(c) Waiver Program Data based on CMS 371 Report, 2018

	Comprehensive Waiver (0178)	HCBS Waiver (0404)	Autism Waiver (0698)	Partnership for Hope Waiver (0841)	MOCDD Waiver (40185)	Total
Total Participants	8,629	3,637	0	2,184	311	14,761
Total Days of Service	2,965,774	1,104,406	0	779,303	73,269	4,922,752
Total Participant Months	97,238	36,210	0	25,551	2,402	161,402
Average Participant Months	11.3	10.0	0	11.7	7.7	10.9
Total Waiver Program Expenditures	$823,618,899	$80,809,628	0	$8,416,976	$2,881,259	$915,726,762
Average Waiver Program Expenditures	$95,448	$22,219	0	$3,854	$9,264	$130,785
Average Non-waiver Medicaid Expenditures	$12,669	$19,030	0	$7,999	$16,449	$56,147
Average Total Medicaid Expenditures for Waiver Program Participants	$108,117	$41,249	0	$11,853	$25,713	$186,932

Another set of programs that is important to supporting health and well-being relates to a continuum of services offered through Long Term Supports and Services (LTSS). These services can be provided in a variety of locations, including both institutional and community settings (Table 9). The goal of LTSS is to

facilitate day to day functioning for people with disabilities, including primary and preventative health efforts. RISP data from the University of Minnesota finds that the majority of Missouri's LTSS recipients receive services in their home. The most recent RISP data from 2018 estimates that there are about 20,000 people with IDD who receive LTSS in Missouri.[xxxviii]

Table 9. Residence of LTSS Recipients with IDD in 2018

Residence Type	Number	Percent of all LTSS Recipients
Family Home	12,115	60.5%
Own Home	4,956	24.8%
Host or Foster Home	489	2.4%
Group Setting (1-6)	1,210	6.0%
Group Setting (7-15)	872	4.4%
Group Setting (16+)	373	1.9%

Data from a 2019 report by the Missouri Department of Social Services estimates that the total number of people receiving LTSS in Missouri is roughly 105,000. This is 39% of the aged, blind and disabled (ABD) population in the state. The provision of LTSS makes up about 70% of the state's total spending on the ABD population and in FY 2018, Missouri spent $2.9 billion on LTSS for this group.[xxxix]

In recent years, Home and Community-Based Services have been more widely encouraged and used throughout the state. In fact, between 2012 and 2016, Missouri had the largest increase in HCBS expenditures as a percentage of total LTSS expenditures out of all 50 states (14.9%).[xl] In 2019, 61% of Missouri's LTSS funds were used for HCBS, which is slightly above the national average of 57%. Although Missouri has a high ranking for change in HCBS expenditures, it ranks below the national average in other performance ratings. For example, Missouri is ranked 49th among states for the percentage of nursing home residents that have low care needs. About a quarter of Missouri's nursing home residents have low care needs, compared to the national average of 11%. This indicates that there are potential opportunities to support these residents in the community rather than institutional care settings.

In Fall 2020, AARP, The Commonwealth Fund and The Scan Foundation released their fourth LTSS State Scorecard. The scorecard measures state LTSS performance on five domains: Affordability and Access, Choice of Setting and Provider, Quality of Life and Quality of Care, Support for Family Caregivers, and Effective Transitions. In 2020, Missouri ranked #30 overall. Missouri received particularly high rankings for Affordability and Access (#3) and particularly low rankings for Quality of Life/Quality of Care and Effective Transitions (#48 for both).

Barrier and Gaps in Information and Resources: Focus on Missouri's Population with IDD

Many individuals with IDD face significant barriers in accessing preventative health care or engaging in health promotion programs and other healthy lifestyles behaviors. Some of the challenges and gaps in health-related services for people with IDD have been acknowledged previously in this report, but this section is specifically dedicated to exploring barriers and gaps in health information, resources, and services for Missourians with IDD. Although the barriers are discussed as separate and distinct forces,

for many individuals, these challenges intersect (for example, when providers aren't available in a region, transportation issues may surface as patients have to travel further for care). Data for this section draws from a variety of data sources and relies heavily on feedback received in the 2020 Missouri Developmental Disability Council Needs Assessment (discussed in the Methodology section).

Availability of Trained Providers

The availability of health care providers presents a challenge for some Missourians. As mentioned, on average, Missouri has fewer primary care providers than the rest of the United States (70 compared to 77 per 100,000 people).[xli] Exploring Health Professional Shortage Areas (HPSAs) designations is another way to understand access to primary, dental, and behavioral health care in Missouri. About 28% of the state's population lives in an area affected by HPSA and of those people, 90% are defined as underserved populations (for example, people experiencing homelessness, low-income populations, those eligible for Medicaid, Native Americans, or migrant farm workers). These rates are higher than those of the U.S. population.[xlii] Needs assessment participants noted that they often experience challenges finding providers due to limitations with insurance coverage, distance to appointments, wait lists, language barriers, and a lack of knowledge on how to best care for individuals with physical or intellectual/developmental disabilities.[xliii]

This last issue—identifying health care providers who are properly trained to serve patients with IDD and mobility limitations and who have knowledge about disability topics—presents a substantial barrier to receiving quality preventative health care services. Locating primary care providers can be challenging enough, but finding specialists who are trained to work with patients with IDD, mobility limitations, or other disabilities is particularly difficult. When health care providers (and their staff) do not have disability-specific knowledge or are not trained in disability-related topics, the quality of patient experiences and care can decline.

Along with a lack of disability knowledge, concerns about how individuals with disabilities are treated also arose in the needs assessment. Some people with disabilities reported having health care experiences in which their provider was discriminatory or assumed inaccurate things about them or their disability based on how they presented in the appointment. Some respondents voiced concern that health professionals do not listen to them or assume they cannot comprehend information.

Confidentiality, and its effect on a patient with disabilities' health care experiences was another matter that was discussed. One participant described a health care provider sharing details of their protected health information with someone who had accompanied them to their appointment, without their permission. They noted, "It seems like they don't think laws apply to people with disabilities."

COVID-19

As noted, many participants identified opportunities to exercise and access physical health resources as important to them. However, COVID-19 disrupted the ability of many Missourians with IDD or mobility limitations to participate in their regular exercise or health promotion activities. Gym closures and social distancing made it difficult for many people to access facilities or feel comfortable participating in exercise

> *"I use aqua therapy to exercise at the Y. Without water, I can't exercise. Missing my cardiovascular aerobics is affecting my health. I hate to see being without this for a couple of years."*
>
> *-Individual with IDD*

or health promotion programs. Some health programming was paused entirely in response to COVID-19, leaving people without access to health facilities, supports or accessible equipment.

Targeted Outreach

Another barrier to accessing health promotion programming identified by listening session participants is in the planning and development of health-related activities. Individuals with disabilities are rarely considered in the initial planning phases of a program and community health programming and outreach materials are not always inclusive. For example, one community service provider in a rural region of Missouri described how a new university-led community walking initiative was piloted in her area. She personally engaged program staff to ensure that the walking program was offered to individuals with disabilities, as outreach to this population was not part of the initial project. This account was substantiated by data collected in a three-phase needs assessment conducted for the Missouri Disability and Health Collaborative in 2017, which focused on individuals with IDD. Participants indicated that a lack of information about available health programs, coupled with concerns that the program will not welcome people with IDD, are barriers to participation in this population.[xliv]

The topic of outreach was also discussed as part of the StationMD evaluation in Missouri. Reaching individuals with IDD and their families—particularly those who weren't connected with a provider or service organization—was a major challenge, and one without a clear solution.[xlv]

Financial Barriers and Health Insurance

CDC data indicate that Missourians with a cognitive disability more commonly report cost as a barrier to seeking medical care than individuals without a disability; nearly a third (32.4%) of people with a cognitive disability reported that they were not able to see a doctor in the past 12 months due to cost, which was the case for 10.5% of those without a disability.[xlvi]

"We see families' insurance getting more restrictive--not only in covering certain types of equipment, but increased deductibles and co-pays."
-Community Service Provider

Needs assessment participants also discussed a need for affordable supports, services, and recreational activities and expressed concern that insurance is increasingly more expensive while covering fewer services.

In addition to individual financial barriers, participants also discussed the shortage of large-scale funding to meet service needs and the importance of investing in public health programs for individuals with IDD. Participants noted concern about funding cuts that cause financial strains on service providers and make it difficult to provide health-related services and supports.

"I know that the economy is tough and so they have to cut budgets here and there. But it seems that always, people with developmental disabilities get the hardest hit."
-Professional

Access to Mental Health Care

The United Health Foundation's state rankings indicate that Missouri ranks #35 in the availability of mental health providers. There are fewer mental health care providers per 100,000 people in Missouri than the U.S. as a whole (204 per 100,000 in Missouri, compared to 262 per 100,000 for U.S.).[xlvii] In line

with these data, participants in the needs assessment indicated that accessing appropriate mental health services in a timely manner was often a challenge for them.[xlviii] They cited long wait lists and a lack of providers in their area as major factors that prevented their families from benefitting from mental health services. Some also discussed the challenge of finding mental health providers who are adequately trained to serve individuals with IDD. This was even more of a barrier when services are needed in a language other than English. When asked about behavioral health care one respondent noted, "You don't hardly have any Spanish speaking counselors or therapists."

> *"Providers, specifically in mental health arenas—so psychologists, psychiatrists—are hard to come by."*
>
> *-Parent of Individual with IDD*

The impact of COVID-19 on the mental health of individuals with IDD, their caregivers, and families was a concern for many Missourians. Respondents mentioned feeling isolated as a result of not being able to see friends and family, losing a sense of purpose without job or volunteer opportunities, additional stressors related to the financial impacts of COVID-19, and anxiety about contracting the virus. Given this context, the need for accessible and appropriate mental health services will likely continue to grow.

34¢

Missouri's per capita spending on transit

47th

Missouri's national ranking for transit funding

Transportation

Transportation is critical to accessing health care, recreational and health promotion services. While there are transportation options statewide, there are still substantial access and utilization barriers. A study by the American Association of State Highway and Transportation Officials reported that Missouri spends considerably less per capita on transit than neighboring states. Missouri spends only 34 cents per capita on transit, while Kansas and Nebraska spend over $3 per capita, Iowa and Tennessee spend more than $5 and Illinois spends $190 per capita. Missouri's funding for transit ranks 47th in the U.S.[xlix]

Though limited, there are several transportation options that are regional or focus on specific populations, including the Non-Emergency Medical Transportation program (which provides free transportation to appointments with Medicaid-covered providers to those who lack access to free transportation),[l] RideKC Freedom (a service where older adults and people with disabilities can schedule low-cost rides in the Kansas City area), and the Rides to Health and Wealth Network, which is currently in development for rural parts of the state.[li] The Missouri Transportation Task Force, which was formed in October 2019, is also working to coordinate transportation options and promote transportation-related collaborations throughout the state.[lii]

Even with these options, many Missourians—in particular, rural Missourians—often struggle to find reliable, efficient, and accessible transportation and most have to travel longer distances to receive needed medical care. As previously mentioned, a shortage of nearby medical facilities and providers and a lack of accessible vehicles contribute to this barrier.[liii]

Health Care Services for Culturally and Linguistically Diverse Populations

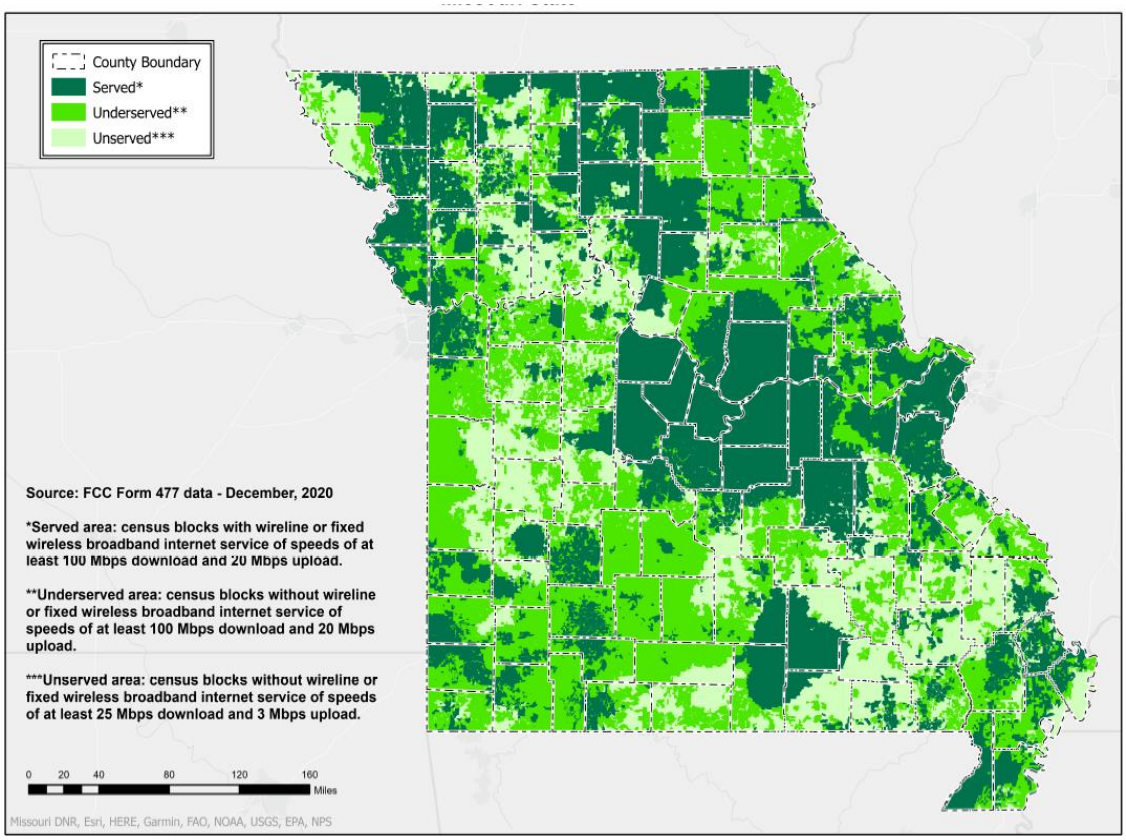
As mentioned, some families reported experiencing greater challenges accessing health care services or medical supports than others. For Hispanic/Latinx families, finding medical and behavioral health providers who can deliver culturally and linguistically sensitive care is difficult. Additionally, medical appointments or health promotion services can be difficult if interpretation services are not dependable or easily available. Several respondents also mentioned encountering financial barriers to receiving health care and experiencing immigration-related challenges to Medicaid enrollment.

These barriers have tangible and disproportionate impacts on the lives of culturally and linguistically diverse Missourians with disabilities and their families. For example, needs assessment respondents were asked to consider their families' future health-related needs. Respondent identifying as Hispanic or Latinx reported a higher rate of anticipated unmet need for adaptive equipment for health and safety, fitness/wellness activities or programs, and access to medical supports and services than their non-Hispanic/Latinx counterparts.[liv]

Telemedicine

While telemedicine can help bridge the gaps in care for people with IDD living in rural parts of the state (and, in the case of StationMD, provide services from clinicians trained to work with individuals with IDD), there continue to be barriers with virtual options. Reliable internet access is one challenge. Figure 4 shows broadband internet coverage for Missouri, and much of the state is either underserved or unserved, particularly in the southwest and southeast regions.[lv] Additionally, many Missourians report struggling with technology literacy, the ability to pay for internet service and devices or both.

Figure 4. Wireline or Fixed Wireless Broadband Speeds Coverage in Missouri



Even when Missourians have access to internet and devices, there are still challenges to using telehealth services among certain populations. Access to telehealth appointments were identified as a particular challenge for individuals not comfortable navigating technology and Spanish-speaking families who indicated that telehealth and technology troubleshooting resources are often not available in Spanish.

Food Security

Between 2017 and 2019, 11.7% of Missourians were considered food insecure and 4.4% were considered to have very low food security based on a scale developed by the USDA[lvi]. UMKC-IHD used the same scale to collect data specifically on individuals and families with IDD in Missouri. Among the sampled population, 18.8% were food insecure and 8.8% had very low food security, which is double that of the general population in Missouri. Prioritizing a healthy and nutritious diet while experiencing food insecurity can be extremely challenging and presents a distinct barrier to those trying to practice healthy eating behaviors.

Rural/Urban Locations

Participants acknowledged that where they live in the state impacts their experiences with the health care system and health promotion activities. As mentioned, rural communities often had few or no local service providers or options for accessible health care or health promotion programs. Many rural participants expressed a high need for information, resources, and education related to a variety of health topics.

While developing a resource guide for this grant's target counties, it became apparent that the majority of services and resources are clustered in and around Missouri's urban centers. Rural counties often have few options for health programming or health resources for individuals with IDD.

Missouri's Governor's Council on Disability

In late 2021, Missouri's Governor's Council on Disability conducted a survey to identify important disability-related issues among Missourians impacted by disability. Of the 528 survey responses, about 40% came from individuals with disabilities (about 40% of those reported a mobility disability and about 20% reported a cognitive disability).

From that survey, the following five topic areas were identified as legislative priorities for 2022:

1. **Public emergency and disaster planning that ensures needs of people with disabilities are met**
2. **All public buildings having evacuation plans for all people with disabilities**
3. **Providing accessible voting machine at each polling location to comply with federal law**
4. **Private insurance covering hearing aids**
5. **The increasing cost of medications**

Health Outcomes and Disparities among Population with Mobility Limitations

Prevalence

According to 2019 estimates from the American Community Survey (ACS), approximately 8.2% of Missourians have an ambulatory difficulty.[lvii] Ambulatory difficulty is defined as having serious difficulty walking or climbing stairs, and although this does not not capture all mobility limitations, it is the closest approximation captured by the U.S. Census. Given Missouri's population of about 6.137 million, there are an estimated 503,230 people living with an ambulatory difficulty in the state. Ambulatory difficulties affect the population at different rates based on age group, with those over 65 years of age reporting the highest rates (22.5%). Table 10 includes data on the percent of the population with an ambulatory difficulty by age group.

Table 10. Percent of Missourians with an Ambulatory/Mobility Difficulty, by Age

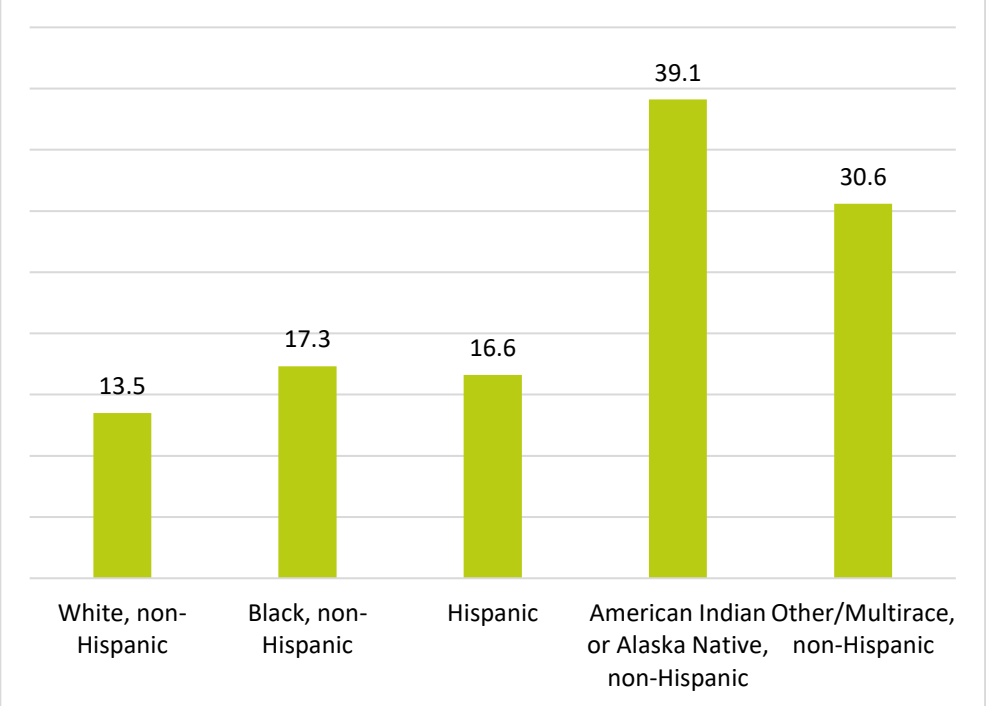
American Community Survey Estimates	
Under 18 years old	0.9%
18-64 years old	6.1%
65 years and over	22.5%
Behavioral Risk Factor Surveillance System Estimates	
18-44 years old	5.2%
45-64 years old	22.1%
65 years and over	29.9%

According to 2019 Disability and Health Data System data, the rate of mobility disability (also defined as having a serious difficulty walking or climbing stairs) among Missourians over the age of 18 was estimated to be 14.5%.[lviii] Using Missouri's population estimates, this would be 951,230 individuals. Again, the highest rates of mobility disability were seen in the population 65 years and older.

Population Demographics

Females reported slightly higher rates of mobility disability than males (16.4% compared to 12.4%).[lix] As shown in Figure 5, among Missourians over the age of 18, American Indian and Alaska Native populations had the highest rates of mobility limitation (39.1%), followed by Other/Multiracial (30.6%), and Black, Non-Hispanic (17.3%).[lx]

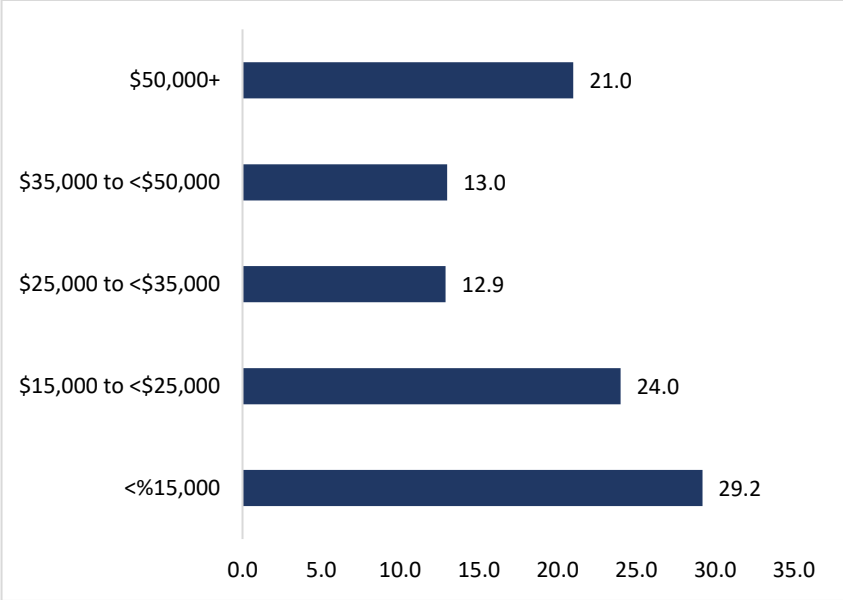
Figure 5. Age-Adjusted Prevalence of Mobility Disability, Adults 18 and Over (%)



In Missouri, individuals with mobility disabilities have lower levels of educational attainment than those without a disability. Nearly 79% of Missourians age 18 and over with a mobility disability have a high school education or higher, while about 93% of Missourians in that age group without a disability have that level of education.

In 2019 in Missouri, there were approximately 55,000 people with ambulatory difficulties employed in the workforce and approximately 160,000 who were not in the labor force.[lxi] Data from the Disability and Health Data System indicate that individuals with disabilities in Missouri have lower incomes than non-disabled individuals. Specifically, about 30% of adults with mobility limitations have an annual income of less than $15,000 while only 5.6% of non-disabled adults have this income level. Nearly four out of five adults with a mobility limitation have an annual income of $50,000 or less (Figure 6).

Figure 6. Annual Income Level Among Adults 18 and Older with Mobility Disability

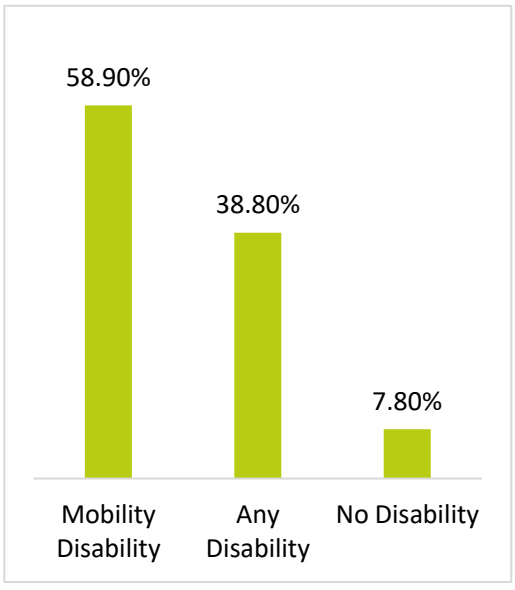


Health Demographics

According to BRFSS estimates, nearly 60% of adults aged 18 and older with a mobility limitation rate their health as fair or poor, which is more than any other disability type and substantially more than the non-disabled population (Figure 7).[lxii] Additionally, among adults with disabilities, those with mobility limitations reported having the most physically unhealthy days in the past 30 days (54.3% reported having 14 or more unhealthy days) than other disability types.

Data from the 2019 BRFSS indicates that individuals with a mobility limitation have higher prevalence rates of all of the surveyed chronic health conditions than people with any disability or those without a disability (Table 11). The prevalence rates of arthritis, asthma, cancer, COPD, diabetes, stroke, heart disease, high blood pressure, and high cholesterol were also higher in the mobility limitation community than in the cognitive disability population.[lxiii]

Figure 7. Percent of Adults Age 18 and Older who Self-Rated their Health as Fair or Poor



Individuals with mobility limitations had the highest rates of high blood pressure (51.7%) of those with a disability, yet only about 62% take medication for this condition. Among the disability population, people with a hearing disability reported the lowest levels of high blood pressure (25.8%), but that group had the most people who reported taking blood pressure medication (83.3%). This indicates that there may be certain barriers to health care access or prescription medication access that are disproportionately affecting individuals with mobility limitations.

Table 11. Chronic Conditions among Adults Age 18 an Older in Missouri, by Disability Status, 2019

Condition	Mobility Disability	Cognitive Disability	Any Disability	No Disability
Ever Had Arthritis	52.4%	42.4%	38.7%	17.0%
Current Asthma	19.2%	17.8%	16.4%	7.8%
Ever Had Cancer (Excluding Skin Cancer)	12.2%	11.9%	9.9%	5.6%
Ever Had COPD	20.2%	18.9%	15.9%	3.8%
Ever Had Diabetes	21.0%	14.3%	13.5%	6.3%
Ever Had a Stroke	11.8%	9.0%	7.2%	1.4%
Ever Had Heart Disease	14.1%	11.4%	10.9%	3.7%
Ever Had High Blood Pressure	51.7%	38.9%	36.9%	23.9%
Ever Had High Cholesterol	40.1%	36.8%	34.8%	26.2%

Engagement with Preventative Health Care

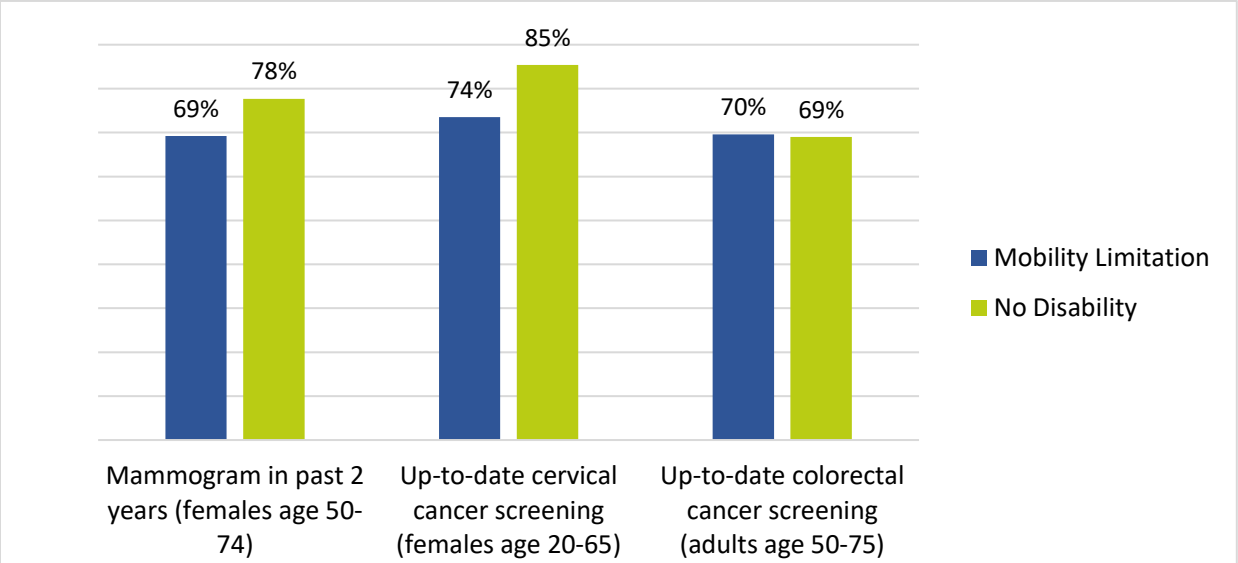
The previous section highlighted health outcomes and health disparities among Missouri's population with mobility limitations. This section focuses on utilization of and engagement with preventative health care services, including primary care, dental care, mental health care, and vaccinations. Additional data pertaining to the disability population or general population can be found in the Engagement with Preventative Health Care in the section focused on Missouri's population with IDD.

Most adults with mobility limitations in Missouri indicate that they have been connected to the health care system in some way in the past year. About 80% of this population reported having had a routine check-up in the past 12 months. This is about 5% higher than both the general population and the disability population. Additionally, about four out of every five adults with mobility disabilities in Missouri report having at least one personal doctor or health care provider, which leaves nearly 20% of the population with mobility limitations who do not have a personal doctor or health care provider.[lxiv]

Nearly a third of people with a mobility disability (31.6%) reported that they could not see a doctor in the past 12 months due to cost.[lxv] This is almost three times higher than the percentage of non-disabled adults who reported that they were unable to see a medical provider due to cost in the past year (10.5%) and signals that financial stress is a barrier to medical care among Missourians with mobility disabilities.

Data on three preventative health screenings (mammograms, and cervical and colorectal cancer screenings) show that for two out of these three screenings, rates of access were lower in the population with mobility limitations than the general population (Figure 8). Although 69% of the eligible mobility disability population had received a mammogram in the past two years, this was nearly 10% lower than the non-disabled population. Similarly, 11% fewer women with mobility disabiltiies had an up-to-date cervical cancer screening than their non-disabled counterparts. Rates of colorectal screenings were similar in the mobility limitation and general population.

Figure 8. Cancer Screenings among Adults with Mobility Disabilities and No Disabilities, 2018



Mental Health

In general, adults with disabilities report having experienced depression in their lifetime more than adults without a disability (46.3% compared to 15.1%). For those with mobility limitations, half reported ever having experienced depression. Nearly 43% also reported having 14 or more mentally unhealthy days in the past 30 days.[lxvi] For adults without disabilities, only 8% reported experiencing 14 or more mentally unhealthy days in the past 30 days.

1 in 2
people with a mobility limitation have experienced depression

Flu Vaccinations

In 2019, 45.1% of Missourians age 18 and over with a mobility limitation had received a flu vaccine in the past year. This closely aligned with the rate of vaccination in the general population, however, it indicates that more than half of adults with mobility disabilities are not accessing flu vaccinations.[lxvii]

Dental Care

In 2018, less than half of adults with a mobility limitation had visited a dentist in the past year. Only 44.3% of respondents indicated that they had received dental care in the past 12 months, which was lower than any other disability type and substantially lower than the use of dental care by the non-disabled population (in which nearly 70% had seen a dentist in the past year). This disparity indicates that there may be significant barriers that deter people with disabilities, and mobility disabilities in particular, from accessing dental care.[lxviii]

Health Insurance Access

While most adults with a mobility disability in Missouri report having health care coverage, 14.4% remain without health insurance.[lxix] Additional information about health insurance coverage among the general disability population can be found in the Engagement with Primary Health care in the section focused on the population IDD.

Practice of Health Lifestyle Behaviors

There are many ways to practice healthy behaviors that happen in the home and community. This section focuses on healthy behaviors and engagement with and access to health promotion programming among Missouri's population with mobility limitations.

Findings from the 2019 BRFSS indicate that individuals with mobility disabilities have higher rates of some health risk factors than the non-disabled population. These risk behaviors include inactivity, being overweight, not meeting physical activity guidelines, smoking and e-cigarette use. Rates of obesity and binge drinking were lower in the mobility disability population than in the general population (Table 12).[lxx]

Table 12. Health Risks and Behavior Topics by Mobility Disability, Missouri 2019

Binge Drinking in the past 30 days				
	Yes	**No**		
Mobility Disability	13.4%	86.6%		
No Disability	18.4%	81.6%		
Body Mass Index				
	Underweight	**Normal Weight**	**Overweight**	**Obese**
Mobility Disability	1.1%	31.5%	35.7%	31.7%
No Disability	+	24.4%	19.9%	52.8%
Aerobic Physical Activity Level				
	Sufficiently Active	**Insufficiently Active**	**Inactive**	
Mobility Disability	28.3%	24.5%	47.2%	
No Disability	47.5%	24.0%	28.5%	
Meets Physical Activity Guidelines				
	Meets both aerobic and muscle strengthening	**Meets aerobic only**	**Meets muscle strengthening only**	**Meets neither**
Mobility Disability	8.5%	21.2%	11.2%	59.1%
No Disability	19.6%	28.1%	11.7%	40.7%
Smoking Status				
	Current Smoker	**Former Smoker**	**Never Smoker**	
Mobility Disability	37.6%	25.1%	37.3%	
No Disability	16.0%	23.6%	60.4%	
Current e-cigarette use				
	Yes	**No**		
Mobility Disability	5.9%	94.1%		
No Disability	5.1%	94.9%		
Ever been tested for HIV				
	Yes	**No**		
Mobility Disability	**48.8%**	**51.2%**		
No Disability	**38.6%**	**61.4%**		
+Data Suppressed. Estimates were suppressed if the standard error was greater than or equal to 30% of the estimate or if the unweighted total population was less than 50.				

Many of the health, wellness, and recreational activities and organizations previously outlined in the IDD section also provide services and recreational opportunities to people with mobility disabilities. For example, the formerly mentioned Disabled Athlete Sports Association, which serves Boone and St. Louis counties, offers sports like wheelchair basketball, power wheelchair soccer, and wheelchair rugby. Refer to the Practice of Healthy Lifestyle Behaviors section focused on individuals with IDD to see other relevant resources.

Additionally, a number of state and county parks offer wheelchair accessible trails, picnic areas, campgrounds, boat launches and restrooms. Figure 9 highlights some accessible features at Washington State Park in Washington County, Missouri. The Missouri Department of Conservation also developed *Disabled-Accessible Outdoors*, a guide to accessible outdoor facilities throughout the state.

Unlimited Play, Inc. is a Missouri-based non-profit dedicated to helping plan, design and build accessible playgrounds throughout the country. The organization has raised funds for the construction of more than 15 accessible playgrounds throughout Missouri.

Figure 9. Accessible Features at Washington State Park

- Picnic Areas: signed parking space, paved pathway, extended-end table, pedestal grill
- Campground: extended-end table, pedestal grill, accessible vault toilets, shower house with roll-in shower with grab bars
- Shelter House: signed parking, paved pathway, accessible water fountain
- Swimming Pool: level, paved parking, accessible seating, accessible restrooms with side transfer toilets, lowered mirrors and clothes hooks, roll-in showers, accessible water fountain

Barriers and Gaps in Information and Resources: Focus on Missouri's Population with Mobility Limitations

Many of the barriers to health care and programming that were explored in-depth previously in this report are also applicable to the population with mobility limitations. This section expounds on some of the specific gaps in preventative health care and health promotion program for the population with mobility limitations, though many of the challenges affecting individuals with IDD are also relevant. This information can be found in the Barriers and Gaps in Information and Resources: Focus on Missouri's Population with IDD section of this report.

Transportation

Some individuals with mobility limitations require specialized vehicles that are fully accessible to people who use wheelchairs, power chairs, or ambulatory assistive devices. In addition to the previously mentioned concerns about transportation access and affordability, individuals with mobility limitations often face additional transportation barriers related to vehicle accessibility. As a result of the Americans with Disabilities Act (ADA), most buses are accessible (by lowering the door-side of the bus towards the curb so commuters will have a smaller step into the bus and by using mechanical lifts). However, challenges with maintaining and operating accessible buses and adequately training drivers so they feel confident using the equipment still remain.[lxxi]

For those using a personal vehicle, modifications can be cost-prohibitive. According to the National Highway Traffic Safety Administration, depending on the adaptive equipment needed, a new modified vehicle can cost between $20,000 and $80,000.[lxxii] Because of these barriers, finding transit options can be especially challenging for people with additional mobility support or accommodation needs.

Accessible Health Care Facilities and Equipment

While some of the difficulties with finding an appropriate medical provider were described in the previous section, individuals with ML may face additional considerations when finding a medical provider. Alongside identifying providers who are covered by insurance, are accepting new patients, have an understanding of disability-related health topics, and are conveniently located, people who experience mobility limitations also must contend with the physical and environmental accessibility of offices or medical facilities. Members of Missouri's Disability and Health Collaborative Steering Committee commented that many offices either are not located in fully accessible buildings or do not have accessible exam rooms.

Even when the building and rooms are accessible, the medical equipment in those rooms (such as exam tables, scales for weighing patients, or assistive transfer equipment) may not be fully accessible. This can make it difficult to perform certain screenings or to obtain accurate medical information, such as a patient's weight.[lxxiii] Inaccessibility can also present challenges at facilities used by people with disabilities to maintain daily functioning, such as physical therapy facilities or massage therapy studios.

Lack of Recreational Services

Although this report highlights several examples of wheelchair accessible recreational spaces, such as parks and campgrounds, these are the exception, not the norm. While regular opportunities to engage in health promotion activities exist in some parts of Missouri, in much of the state there are few options and most recreational spaces throughout the state were not designed with inclusion in mind. Missouri's Disability and Health Collaborative Steering Committee members noted that when there are available recreational resources, most host a very limited number of events each year instead of regular opportunities for engagement. A review of the aforementioned resources substantiated this. While there are very few accessible recreation and sports options in Missouri, this is particularly true in more rural counties. One listening session participant said, "There are some options if you live in the St. Louis or Kansas City area, but if you live outside those areas there is basically nothing." In smaller towns and rural regions of the state, not only is there a dearth of organized inclusive activities, even going to a park can be difficult due to accessibility concerns. This can present substantial barriers for individuals looking to be active.

Entities such as the YMCA or University of Missouri Extension offices offer health promotion programming throughout the state that is often free or low cost. However, these programs are not always developed to be accessible to individuals with mobility limitation or do not clearly include people with mobility limitations in marketing materials.

Need for Trained Staff

In addition to the previously mentioned need for adequately trained health care providers, partnering community organizations also noted that there is a lack of trained staff to administer health programming to individuals with mobility limitations. Organizations indicated that they would like to offer more evidence-based health promotion programming to Missouri's disability population, but

because of shortages in trained staff (and training opportunities for staff), they are unable to implement these programs. Recommended areas of training for service providers of all varieties include topics such as person-first language, basics of the ADA, and inclusive programming.

Lack of Data

In developing this report, and a resource guide with health-related information and resources for Missourians with mobility limitations, the research team noted a scarcity of data and resources pertaining specifically to individuals with a mobility limitation. A lack of data and visibility of accessibility issues can stymie important work to increase the inclusivity of health care services and health promotion activities among this population.

Additionally, there is a need for community organizations to collect data around the disability status and support needs of their members. This information can help organizations better understand if they are reaching people with disabilities and addressing their support needs. It can also help them understand if certain program out outreach efforts are effective in connecting with people with disabilities.onclusion

Individuals with IDD and/or mobility limitations are at increased risk for poor health outcomes and experience higher rates of chronic disease than those without a disability.[lxxiv] Individuals with disabilities are more likely to report having poorer overall health, having less access to adequate health care or health screening services, and participating in more risky behaviors than people without a disability.[lxxv,

[lxxvi] Barriers to accessing health care services and health promotion programming and activities are associated with an increase in preventable health conditions or secondary health conditions that negatively impact general health and quality of life among individuals with disabilities. Some of the primary barriers that individuals with a mobility limitation or IDD in Missouri are currently facing include:

- Limited availability of appropriately **trained health care providers**
- **High cost** of medical care and health promotion activities
- Lack of accessible, affordable, and reliable modes of **transportation**
- Little **strategic marketing, outreach or promotion** of inclusive programming
- Dearth of **accessible health care provider facilities and recreational activities**
- Accessible services, health care, and recreational activities are scarce in **rural areas**

Recommendations

Efforts to mitigate the barriers to preventative health care and health promotion activities experience by individuals with disabilities must be multi-pronged and inclusive. Some recommendations to address barriers to accessing health care and health promotion programming among those with an IDD and/or a ML include:

- **Increased opportunities for training among health care providers** of all levels (doctors, nurses, medical assistants, etc.) and office staff to equip them with the knowledge and skill to provide accessible care and services.

- **Increased training opportunities among health promotion program staff** to emphasize the importance of accessible and inclusive programming and educate how to effectively adapt programs to be inviting to all populations.
- **Increased use of inclusive marketing materials** that include accessible language and images of people with disabilities to promote awareness of accessible health promotion programs and activities.
- **Create and expand interagency partnerships** that support efforts to provide regular, accessible health programming and disseminate information about accessible programs throughout the state.
- **Increased accessible public transit options** that are reliable, affordable, and inclusive.
- **Increased education and resources** for people with disabilities on healthy behaviors, accessible health programs and health care providers who are skilled in working with individuals with disabilities.
- **Targeted local and regional capacity building opportunities** to increase availability of accessible health care and health promotion program options and build the infrastructure to support accessible health-related supports.
- **Increased focus on sustainability of accessible and inclusive health care and health promotion program initiatives** through policy, systems, and environmental changes.

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