Comprehensive Review and Analysis

February 28, 2021

Contents

TABLE OF TABLES

TABLE OF FIGURES

INTRODUCTION

The Missouri Developmental Disabilities Council (MODDC) began planning for the 2022-2027 five-year state plan in late 2019. MODDC funded the University of Missouri-Kansas City Institute for Human Development (UMKC-IHD) to develop the Comprehensive Review and Analysis of needed systems change and capacity building related to services and supports for people with intellectual and developmental disabilities (IDD) in Missouri. In the early planning period, MODDC worked with UMKC-IHD to establish a timeline and process for the CRA development.

Throughout the process, MODDC and UMKC-IHD worked with a statewide network of partners and followed ITACC guidance to gather data to inform actionable, community-driven policy and program recommendations. In early spring 2020, UMKC-IHD began compiling the CRA, gathering relevant existing data and developing a strategy to collect qualitative and quantitative data from a diverse range of Missourians with IDD and stakeholders. MODDC and UMKC-IHD leadership and staff met several times to create a plan and were in regular communication regarding relevant data sources. UMKC-IHD made two presentations of findings to the MODDC.

As in 2016, a Needs Assessment survey was developed to gather data from self-advocates, families, professionals in the IDD field, and other stakeholders. This survey was developed by UMKC-IHD and reviewed by the MODDC. All suggested edits to the survey (largely the addition of several questions related to food security and emergency preparedness) were made. After the survey was finalized, it was translated into Spanish and reviewed by two Spanish-speaking staff members. English and Spanish versions of the survey were published online. Paper copies of the survey were also made available to professionals meeting with families in person. The survey was open from late July until the end of October 2020.

Various community partners across the state assisted with dissemination by promoting the survey on organizational listservs, websites, social media posts, and more. Many organizations sent multiple emails or included information about the survey in multiple newsletters. UMKC-IHD publicized the survey through social media and email blasts and promoted it during the 13 listening sessions and five interviews held between July and October. Information about the survey was shared through MODDC's website. Partner agencies that assisted with dissemination include: MODDC, People First of Missouri, Missouri Family to Family, local county disability services (SB-40) boards, ABiLITY, and Association on Aging with Developmental Disabilities. A partnership with Alianzas allowed for greater outreach to Missouri's Latinx community. Alianzas staff members did substantial online and phone outreach to program members and affiliated organizations to promote the survey.

A total of 623 surveys were completed statewide, 616 in English and seven in Spanish, far exceeding the initial goal of 220 responses outlined in the workplan.

In addition to the Needs Assessment survey, community listening sessions were held to gather qualitative data and hear directly from Missourians in a different format. Between July-October 2020, UMKC-IHD staff members hosted 13 listening sessions: 11 regional sessions, one for People First of Missouri members, and one Spanish language session. Accommodations were offered at all listening sessions. The listening sessions were facilitated by two research team members, one of whom is a self-advocate, and were attended by a third team member who took notes. Sessions were conducted using a

prepared script and the three team members met after each session to discuss main themes and review notes.

The 11 regional sessions were held in July-August. After their completion, the research team determined that in these sessions, there were gaps in representation of self-advocates and rural and Latinx population. As a result, the research team and project partners convened two additional sessions, one with self-advocates as a part of the People First of Missouri annual conference and one with Latinx family members and self-advocates (conducted in Spanish). In addition, one interview was conducted with a professional who works closely with Latinx families in the community. To ensure representation from rural areas--in particular Southeast Missouri, where listening session attendance was low--project staff conducted individual phone interviews with four parents/professionals from the region. Overall, 84 people participated in a listening session or interview. Listening sessions and individual interviews were recorded, transcribed verbatim and coded using qualitative data analysis software (Atlas.ti).

In addition to gathering existing data and collecting data through the Needs Assessment and listening sessions, a thorough review of relevant committee meeting minutes was completed to determine if there were any themes surfacing that data collection activities had not yet captured. For example, the research team reviewed minutes from the Access and Functional Needs Committee, which is a group of statewide leaders focused on policy and systems change, to determine if any new themes emerged in their discussions. In 2020, MODDC held over a dozen *Coffee with Katheryne* events, which were virtual meetings for self-advocates and family members to discuss their experiences and share concerns. The notes from these events were also analyzed for new themes. Feedback that was submitted through MODDC's Scholarship Satisfaction Survey was also reviewed. While no additional themes emerged from this document review, the minutes from these events provide valuable context for the CRA.

STATE DISABILITY CHARACTERISTICS

The following section details information about Missouri's overall population and IDD population, including information related to prevalence and demographics.

PREVELANCE OF DD IN STATE AND EXPLANATION OF PREVALENCE

Accurately estimating the prevalence of disability in a population is challenging, and there are multiple accepted measures of prevalence. Several studies have researched the prevalence or developmental disabilities, though Larson et al.'s (2001) estimate of 1.58% prevalence rate in a population is one of the most widely accepted.[i] Additional studies shared by the Office of Developmental Disabilities calculate the prevalence rate to be as low as .76%[ii] and as high as 1.7%.[iii] Based on these estimations and Missouri's population of roughly 6.137 million, there are likely between 46,641 (.76%) and 104,329 (1.7%) Missourians 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

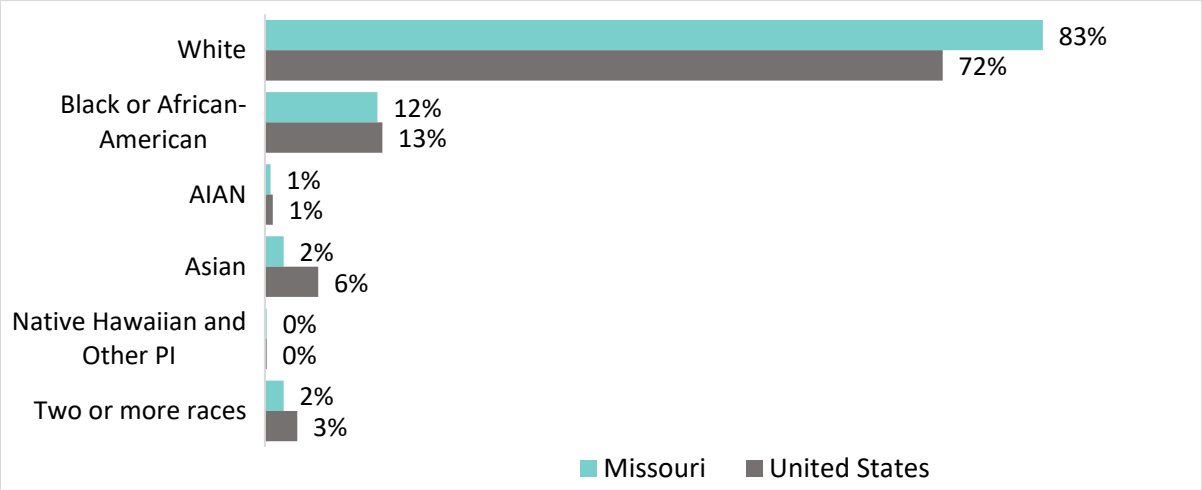
Data for this CRA comes from a variety of sources. Available sources often differ by sample population and definition of disability. Because of this, data must be understood and interpreted in context. For example, much of the demographic information in this report comes from the U.S. Census, which collects data on physical and cognitive disabilities through the American Community Survey (ACS). While the ACS gathers data on cognitive disabilities, the operational definition of cognitive disability used ("because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions") does not directly align with other accepted definitions of IDD.[iv] However, because the ACS has a large, nationwide sample of disability and other data, it remains a valuable resource and is the recommended source by ITACC.

According to the 2019 ACS 1-Year Estimates, approximately 14.7% of the population, or 887,896 Missourians, have a disability of some kind and 6.1% or 345,053 have a cognitive disability. Nationwide, 12.6% of the population has a disability of some kind and 5.2% have a cognitive disability.[v]

RACIAL AND ETHNIC DIVERSITY OF THE STATE POPULATION

According to the 2019 ACS, Missouri's population of just over 6.1 million people is roughly 83% white, 12% Black or African-American, 2% two or more races, 2% Asian, and less than 1% American Indian or Alaska Native and Native Hawaiian or other Pacific Islander (Figure 1).[vi]

Figure 1. Percent of Population by Race, 2019



LANGUAGE SPOKEN AT HOME

In Missouri in 2018, 93.7% of people spoke English at home, while 6.3% of the population spoke another language at home. Among the 6.3% who speak another language at home, 98% reported speaking English "very well" or better, indicating a high level of comfort with English by most Missourians.

Besides English, the most common language spoken at home was Spanish (2.5% of Missouri's population--and 40% of those speaking another language at home--spoke Spanish, Table 2). Although English is widely spoken in Missouri, numerous other languages are also represented in the state's population and targeted outreach in other languages—particularly Spanish—can help decrease language barriers experienced by individuals and families.[vii]

Tables 2 and 3 provide more detailed information about the language spoken at home by Missourians.

Table 2. Language Spoken at Home in Missouri, 2018		
Language	**Number**	**% of Population**
Total Households Speaking A Language other than English	363,864	6.3%
Spanish	144,847	2.5%
Other Indo-European Languages	105,157	1.8%
Asian And Pacific Island Languages	77,154	1.3%
Other Languages	36,706	.6%

Table 3. Languages Spoken at Home for Population 5 Years and Older, 2019[viii]			
	MO Population 5 Years and Older	**% of MO Population 5 Years and Older**	**Disabled Estimate 5 Year and Older**
Total Population	5,717,130	100%	870,836
English Only	5,367,705	94%	817,611
Language other than English	349,425	6%	53,225
Speak English less than "very well"	114,400	2%	17,425
Spanish	145,831	2.55%	22,213
Speak English less than "very well"	52,262	.91%	7,961
French, Haitian, or Cajun	12,460	.22%	1,898
Speak English less than "very well"	2,725	.05%	415
German or West Germanic languages	30,004	.52%	4,570
Speak English less than "very well"	7,122	.12%	1,085
Russian, Polish or other Slavic languages	23,559	.41%	3,589
Speak English less than "very well"	8,769	.15%	1,336
Other Indo-European languages	33,898	.59%	5,163
Speak English less than "very well"	9,773	.17%	1,489
Korean	6,803	.12%	1,036
Speak English less than "very well"	3,786	.07%	577
Chinese (incl. Mandarin, Cantonese)	21,988	.38%	3,349
Speak English less than "very well"	11,111	.19%	1,692
Vietnamese	13,451	.24%	2,049
Speak English less than "very well"	7,802	.14%	1,188
Tagalog (incl. Filipino)	7,618	.13%	1,160
Speak English less than "very well"	2,285	.04%	348
Other Asian and Pacific Island languages	22,554	.39%	3,435
Speak English less than "very well"	7,917	.14%	1,206
Arabic	12,539	.22%	1,910
Speak English less than "very well"	4,649	.08%	708
Other and unspecified languages	18,720	.33%	2,851
Speak English less than "very well"	5,972	.10%	910

RESIDENTIAL SETTINGS

There are currently 4 habilitation centers operating in Missouri: Bellefontaine Habilitation Center, Higginsville Habilitation Center, St. Charles Habilitation Center and South County Habilitations Center. [ix] In recent years, Missouri has been closing and consolidating its Habilitation Centers in favor of community-based services. The four centers still in operation primarily serve residents who were already living there and no longer admit individuals for long-term residential placement. Current habilitation admissions are exclusively for short-term crisis stabilization. Some habilitation center residents have Missouri's Home and Community Based Waiver Program and receive service coordination and monitoring, like waiver recipients living in other settings.[x]

Habilitation Centers and COVID-19

All four of Missouri's habilitation centers experienced diagnosed cases of COVID-19 among staff and residents during the COVID-19 pandemic. As of February 1, 2021, 144 staff members at Bellefontaine, 81 staff members at South County, 62 staff members at St. Charles, and 96 staff members at Higginsville have tested positive for COVID-19. All four facilities also had COVID-19 cases among residents: 35 at Bellefontaine, 27 at South County, 19 at St. Charles and 33 at Higginsville. Six residents and two staff members of habilitation centers died of COVID-19: 2 residents from Bellefontaine, 2 residents and 1 staff from South County, and 2 residents and 1 staff from Higginsville.[xi]

Missouri receives funding from the Money Follows the Person Grant, which has the goal "to support people who have disabilities and those who are aging to move from a nursing facility or habilitation center to a quality community setting that meets their needs and wants." Since Missouri joined this program in 2007, the number of individuals living in congregate settings with 7 or more people has steadily decreased and community settings have been favored over larger institutional settings.[xii]

Most Missourians who receive Long-Term Supports and Services (LTSS) live in their family home (58.4%) or their own home (24.4%), while 17.1% live in a host, foster home, or group setting. Of the approximately 3,224 people living in a residential setting in 2016, 420 (or 2.2% of Missourians receiving LTSS) resided in a group setting with 16 or more people. This is below the national average of 3.2%.[xiii]

Similarly, data from the State of the States shows that from 2007 to 2017, the number of people living in congregate settings with 16 or more people steadily declined, while the number of people living in settings with six or fewer people consistently rose. The most recent data from 2017 indicate that 11.5% of LTSS recipients live in a residential setting (nursing facility, state institution, private ICF/ID, or other residential setting) with 16 or more other people and 82.9% live in a setting (public ICF/ID, private ICF/ID, supported living, or other residential setting) with 6 or fewer people. [xiv]

Table 4, adapted from the State of the States, provides the number of people in Missouri living in residential settings.

Table 4. Persons Served by Setting, FY 2007-2017											
	2007	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**
Total	11,054	11,336	10,493	10,973	11,685	11,617	11,842	12,365	12,384	12,758	13,105
16+ Persons	2,477	2,410,	2,380	2,192	2,120	1,849	1,557	1,566	1,603	1,672	1,504
Nursing Facilities	1,401	1,398	1,386	1,450	1,440	1,226	959	1,024	1,089	1,180	1,056
State Institutions	944	882	873	611	552	492	465	441	415	365	339
Private ICF/ID	30	32	29	31	31	31	31	0	0	34	34
Other Residential	102	98	92	100	96	100	102	101	99	93	75
7-15 Persons	2,222	2,317	1,492	1,431	1,269	934	867	1,132	1,092	926	944
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	50	50	47	51	54	56	52	53	49	53	53
Other Residential	2,172	2,267	1,445	1,380	1,215	878	815	1,079	1,043	873	891
6 or Fewer Persons	6,355	6,609	6,621	7,350	8,296	8,834	9,418	9,667	9,689	10,158	10,657
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	6	6	6	6	7	4	0	0	0	0	0
Supported Living	4,634	4,889	4,804	5,581	6,434	7,067	7,563	7,832	8,000	8,337	8,870
Other Residential	1,715	1,714	1,811	1,763	1,855	1,763	1,855	1,835	1,689	1,821	1,787

Key Points

- There is no single agreed upon estimate of the number of people living with IDD, but widely accepted prevalence rate suggests that in Missouri, there are approximately 97,000 individuals with IDD.
- Missouri's population is largely white (82%) and English speaking (94%). Approximately 11% of the population identifies as Black or African American and among the 6% of Missourians who speak another language at home, Spanish is the most commonly spoken language (2.6%).
- Most Missourians receiving LTSS reside at their family home or in their own home.
- The population of Missourians with IDD living in nursing facilities, ICF/ID, and other group residential settings has been declining since 2007 as part of the Money Follows the Person grant, as well as HCBS. Many Missourians with IDD are living in the community and the number of habilitation centers in the state has decreased to four.

DEMOGRAPHICS OF POPULATION WITH DISABILITIES

Age

The rate of cognitive disability in Missouri's population increases with age. Cognitive disability prevalence is highest in the oldest age group (11.6% for those 75 years of age and older), and lowest in the youngest age group (4.9% for those under 18).[xv] This trend is likely impacted by the previously discussed definition of cognitive disability used by the ACS. Table 5 contains Missouri's cognitive disability population broken down by age groups.

Table 5. Disability Prevalence by Age in Missouri, 2019

Age Group (in years)	Number with a Cognitive Disability	% of Population with a Cognitive Disability
Under 18	49,497	4.9%
18 to 34	69, 536	5.2%
35 to 64	139,732	6.1%
65 to 74	37,400	6.2%
75 and over	48,898	11.6%

Disability Type

According to U.S. Census data, approximately 14.7% of Missourians (887,896) have a disability of some kind, which is slightly higher than the national disability prevalence rate of 12.6%.[xvi] Among adults over the age of 18, approximately 28.8% of Missourians have a disability, which is also higher than the national average (26.0%, Table 6). Mobility disabilities are the most common type of disability and self-care disabilities are the least common in Missouri's population. Across all disability types, the percentage of people living with a disability is higher in Missouri than the U.S. average. [xvii]

Table 6. Disability Status by Types Among Adults 18 Years of Age or Older

	Percent in Missouri	Percent in the U.S.
Adults with any disability	28.8%	26.0%
Adults with a hearing disability	7.6%	5.9%
Adults with a cognitive disability	12.4%	11.5%
Adults with a mobility disability	14.6%	12.4%
Adults with a vision disability	5.7%	5.0%
Adults with a self-care disability	4.6%	3.5%
Adults with an independent living disability	9.0%	6.8%

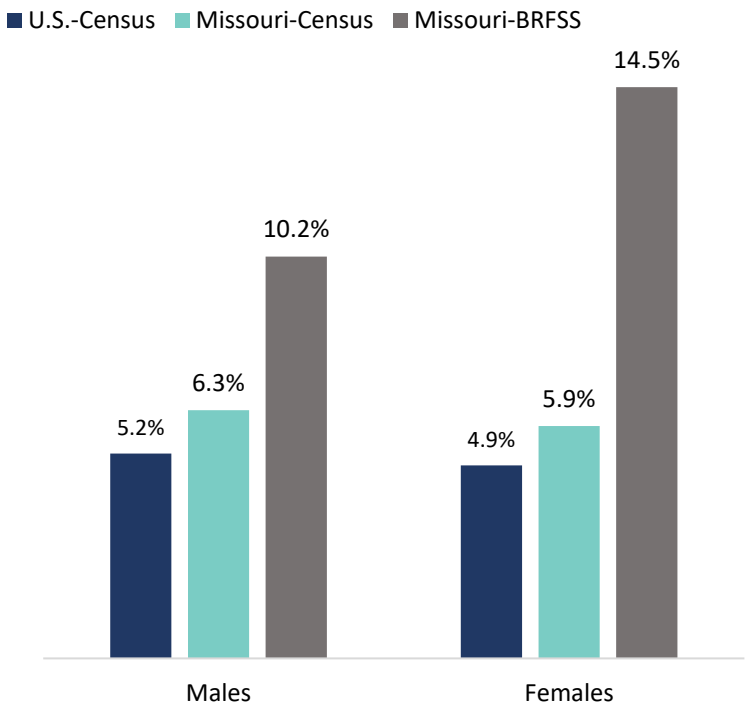
Gender

In Missouri, males and females have similar rates of disability (across all six disability types: hearing, cognitive, mobility, vision, self-care, and independent living), both at 14% of the population. This aligns with national trends of disability, where prevalence is roughly equal between genders.[xviii]

For cognitive disability specifically, there are varying estimates in Missouri (Figure 2), likely due to differences in definition of cognitive disability. Census data indicates that females in Missouri (and in the nation) had a slightly lower prevalence (5.9%) than males (6.3%).[xix]

Data from the Behavioral Risk Factor Surveillance System (BRFSS) survey, which collects data on adults over the age of 18, has a higher prevalence rate of cognitive disabilities in females (14.5%) than males (10.2%). The higher prevalence rates for BRFSS are likely due to the age of respondents (surveys an exclusively adult population).

Figure 2. Cognitive Disability by Gender, 2018



Hispanic/Latino Ethnicity

Nearly 225,500 Missourians identify as Hispanic or Latino in the Census. According to data from the American Community Survey, Missourians who are Hispanic/Latino have a lower disability prevalence rate than Missourians who are not Hispanic/Latino.[xx] This holds true for cognitive disabilities. Approximately 4.9% of Missourians who are Hispanic/Latino have a cognitive disability while 6.1% of Missourians who do not identify as Hispanic/Latino have a cognitive disability (Table 7).

Table 7. Missourians with a Cognitive Disability by Hispanic/Latino Ethnicity

Ethnicity	Number with a Disability	Number with a Cognitive Disability	Percent with a Disability	Percent with Cognitive Disability
Hispanic/Latino	20,741	11,045	8.4%	4.9%
Not Hispanic/Latino	717,182	331,785	15.0%	6.1%

Race

As mentioned above, Missouri's population of just over 6.1 million people is over 80% white, 12% Black or African-American, 2% two or more races, 2% Asian, 1% some other race, and less than 1% American Indian or Alaska Native and Native Hawaiian or other Pacific Islander. Rates of disability are not consistent across racial groups, and racial disparities in disability prevalence exist.

The prevalence of disability is highest among Missourians who identify as American Indian and Alaska Native. The AIAN population has the highest rate of disability (28.2%), followed by the Black or African American population (15.7%, Table 8).[xxi] The lowest rates of disability were seen among those identifying as Asian (6.4%). The rates of cognitive disability were highest among people who identified as Some Other Race (8.2%) and lowest among those identifying as Asian (2.5%). [xxii]

The percent of people with a disability in Missouri is higher than the U.S prevalence in four of the seven racial groups (Figures 3 and 4).[xxiii]

Table 8. Population of Missouri by Race and Disability Status, 2019

Race	Population	Percent with a Disability	Percent with a Cognitive Disability*
White	5,022,939	14.9%	5.9%
Black or African American	703,058	15.7%	7.6%
American Indian and Alaska Native	25,516	28.2%	5.3%
Asian	127,154	6.4%	2.5%
Native Hawaiian and Other Pacific Islander	10,214	9.5%	No Data
Some other race	76,294	7.4%	8.2%
Two or more races	172,253	13.2%	No Data

*2018 data from Disabilitystatistics.org

Figure 3. Percent of Population with a Disability by Race

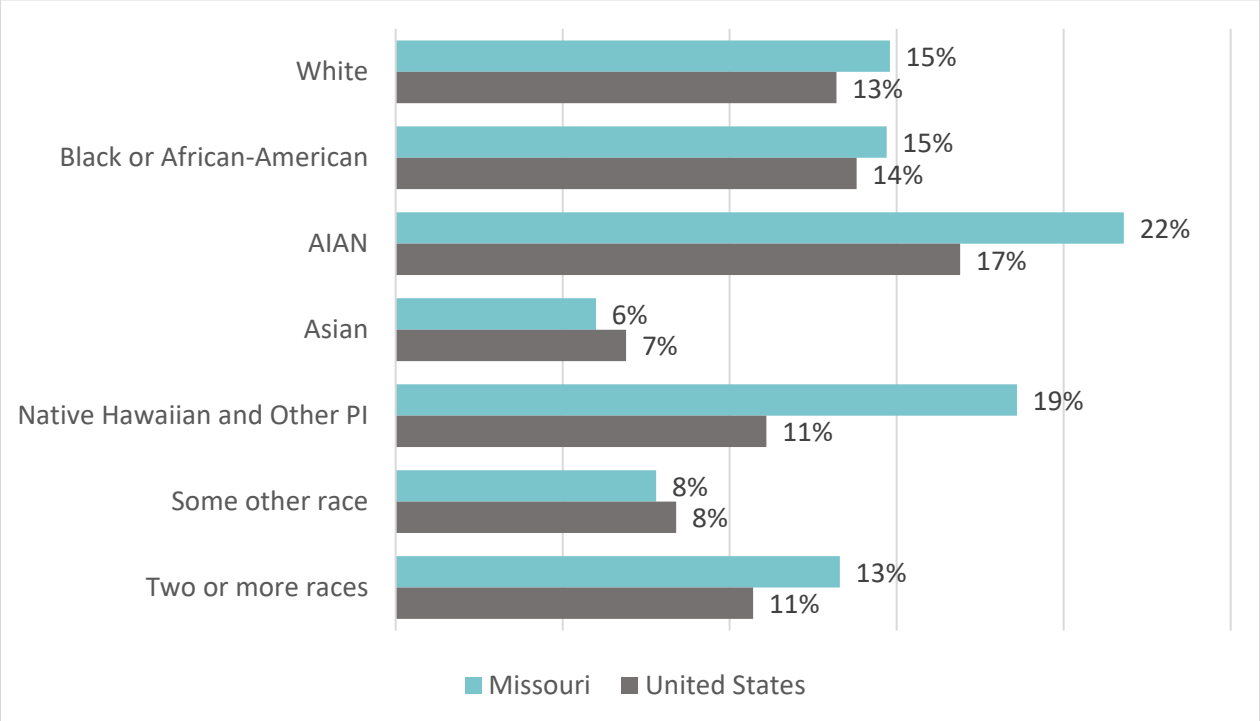
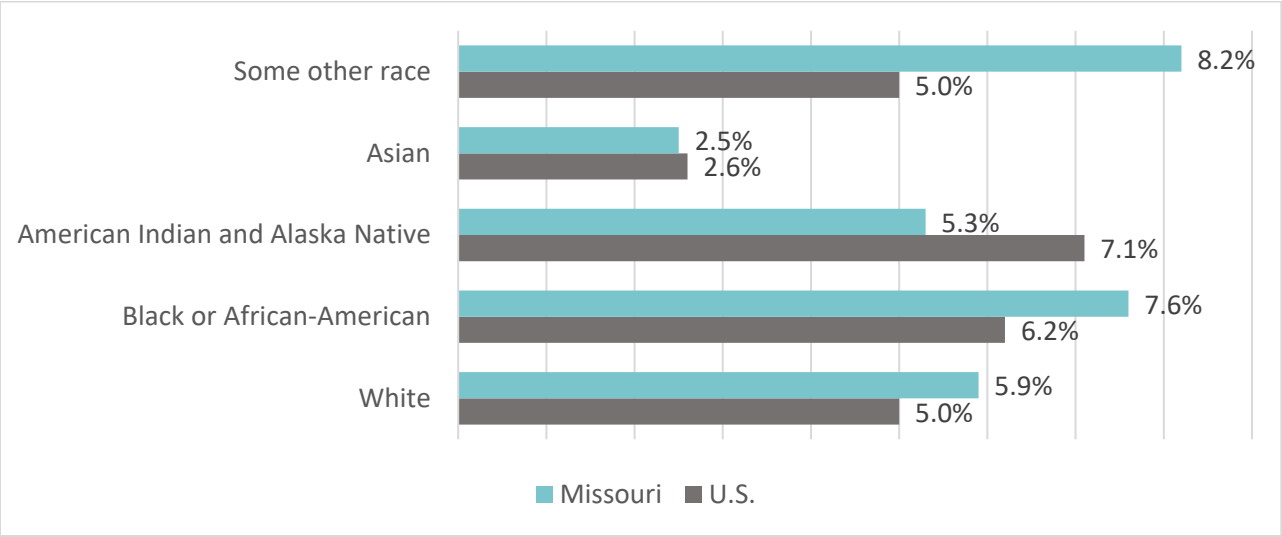


Figure 4. Cognitive Disability by Race, 2018



EDUCATIONAL ATTAINMENT, 25 AND OVER

Educational attainment among people with a disability is lower than for those without a disability. In Missouri, nearly one fifth (18.3%) of people with a disability have less than a high school education, compared to just 6.7% of people without a disability (Table 9). However, the percentage of people who had some college experience or an Associate Degree was similar for people with and without disabilities (32.6% and 33.5%, respectively).[xxiv]

Table 9. Educational Attainment by Disability Status in MO, 2018
(non-institutionalized persons aged 21-64)

	With a disability	With a cognitive disability	Without a disability
Less than high school education	18.3%	20.8%	6.7%
High school diploma or equivalent	37.6%	38.8%	26.0%
Some college or Associate Degree	32.6%	30.6%	33.5%
BA or higher	11.5%	9.8%	33.8%

People with cognitive disabilities had lower rates of educational attainment than average for all disability types. Nearly 60% of Missourians with a cognitive disability have a high school diploma or equivalent or less.

EMPLOYMENT STATUS

Missourians with a disability are far less likely to be employed than their peers without disabilities. The employment rate for people with disabilities aged 16-64 was 36.1% in 2018. It was 81.7% for people without disabilities. Approximately 172,000 Missourians with disabilities were employed in 2018, while 19,300 were unemployed and 268,000 were not in the work force.

From 2015-2017, the percent of people with a cognitive disability in Missouri who were in the workforce rose slightly from 26.2% to 28.7% (Table 10).[xxv]

Table 10. Employment Participation for Working-Age People (16-64), 2015-2017[xxvi]			
	2015	2016	2017
Number of People with No Disability	3,357,026	3,335,208	3,327,113
Number of People with Any Disability	476,576	478,679	476,228
Number of People with a Cognitive Disability	214,160	215,392	212,900
Number of People with No Disability who are Employed	2,576,411	2,569,828	2,581,906
Number of People with Any Disability who are Employed	160,958	162,427	169,487
Number of People with a Cognitive Disability who are Employed	56,124	54,007	61,054
Percent of People with No Disability who are Employed	76.7%	77.0%	77.6%
Percent of People with Any Disability who are Employed	33.8%	33.9%	35.6%
Percent of People with a Cognitive Disability who are Employed	26.2%	25.1%	28.7%

EARNINGS IN THE PAST 12 MONTHS, 16 AND OVER

As shown above, people with disabilities are less likely to be employed than their counterparts without a disability. When people with a disability are employed, their earnings are often less than workers without a disability. Over half (54.6%) of workers with a disability make less than $25,000 a year while 36.6% of workers without a disability make less than $25,000 a year. Less than 20% of workers with a disability (17.9%) make more than $50,000 a year (Table 11).

Table 11. Earnings in Past 12 Months of Missourians Aged 16 and Over with Earnings, 2018[xxvii]		
Earnings	**With a Disability**	**No Disability**
$1 to $4,999 or less	17.8%	9.6%
$5,000 to $14,999	21.2%	13.2%
$15,000 to $24,999	15.6%	13.8%
$25,000 to $34,999	14.0%	14.8%
$35,000 to $49,999	13.4%	16.9%
$50,000 to $74,999	10.2%	16.5%
$75,000 or more	7.7%	15.2%

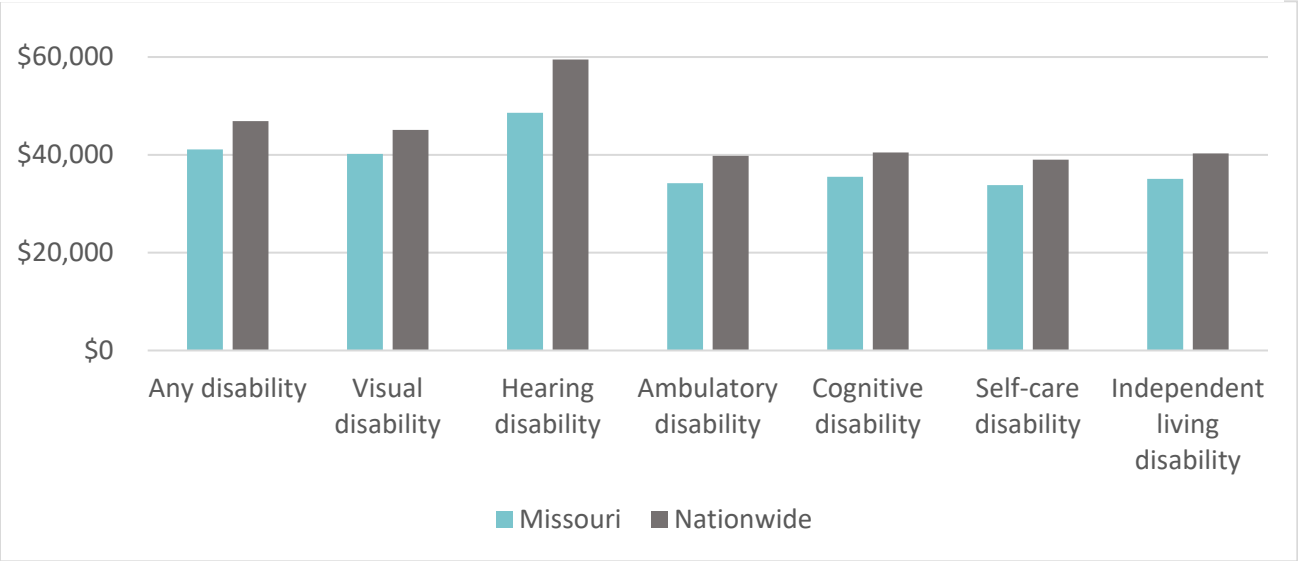
In 2018 in Missouri, the median income of workers with a disability was $21,577, which is almost $12,000 lower than the median annual income of their counterparts without a disability.[xxviii]

Annual Median Income of Missourians (2018)

With a Disability	Without a Disability
$21,577	$33,456

A similar trend also exists for median household income. Missouri's median household income for people with disabilities is lower than for households with no family members with a disability and it also lower than the national average. Households that include someone aged 21-64 with a disability in Missouri have an annual median income of $5,800 less than similar households across the U.S. Missouri's household income lags behind the national average for all types of disabilities, though the exact amount varies by disability type. People with cognitive disabilities in Missouri have a median annual household income that is $5,000 less than the national median household income ($35,500 as compared to the $40,500 national median income, Figure 5).[xxix]

Figure 5. Median Annual Household Income by Disability Type, 2018



POVERTY STATUS, 16 AND OVER

Missouri's poverty rate is 12.9%.[xxx] Individuals with disabilities are more likely than those without disabilities to live in poverty. Based on data from the 2018 American Community Survey, 28.2% of individuals with a disability between the ages of 21-64 live below the poverty line.[xxxi] The national poverty rate for individuals with a disability was 26%, slightly lower than that of Missouri. Approximately one-third (33.8%) of Missourians with a cognitive disability lived below the poverty line in 2018.[xxxii] The poverty rate for Missourians who do not have a disability is just under 10%, indicating that the burden of poverty falls heavily on those with disabilities.

Poverty Rate for Missourians with a Disability: → **28.2%**

Poverty Rate for Missourians with a Cognitive Disability: → **33.8%**

Poverty Rate for Missourians Without a Disability: → **9.7%**

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[xxxiii]. UMKC-IHD used the same scale to collect data 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.

Key Points

- Understanding state disability demographics can shed light on patterns, frame issues in context, and indicate where to deploy resources in the future.
- Disability rates increase with age, with the oldest Missourians having the highest rates of disability (47.9%). Men and women have similar rates of disabilities, except for cognitive disability, where rates vary by data source.

- There are racial disparities in the rates of disabilities experienced by Missourians. American Indian and Alaska Natives and Native Hawaiian and Other Pacific Islanders had the highest rates of disability in Missouri.
- People with cognitive disabilities in Missouri have lower levels of educational attainment and lower rates of employment than the general population.
- Household incomes are often lower in households that include a person with a disability. Over 50% of people with a disability earn less than $25,000 a year and the median income for this population is roughly $12,000 a year less than their peers without a disability. This leaves many people with disabilities and their families in precarious financial situations.
- In Missouri, the poverty rate for people with disabilities is 28% and it's even higher for those with a cognitive disability (34%). These rates are considerably higher than the poverty rate for those without disabilities (10%).

PORTRAIT OF STATE SERVICES

RECREATION

Missouri offers a variety of recreation-related services to individuals with IDD and their families. Several notable supports and programs are highlighted below:

Missouri is home to five chapters of The Arc, a non-profit organization dedicated to advocating for, and with, people with IDD and their families. The Arc chapters offer a variety of supports and services, with specific initiatives and programs varying by chapter. Often, Arc chapters offer residential, educational, employment and recreational services. The Arc of the Ozarks, for example offers accessible recreation options at the Timothy Grant Newport Activity Center, which is equipped to safely serve individuals with disabilities. The Arc of Clay and Platte Counties, Inc. has residential summer camps, bowling teams, a toy lending library, and leads social events for participants.[xxxiv] The No Limits Summer Recreation program is a multi-week summer Arc program for young adults ages 6-21 with IDD. Participants play games, attend field trips, do arts and crafts, and learn daily living and social skills.[xxxv] Unfortunately, many recreation activities, including the No Limits Summer program, were cancelled in 2020 due to the coronavirus pandemic.

Missouri Chapters of The Arc

- Arc of Northeast Missouri: Kirksville
- St. Louis Arc: St. Louis
- The Arc of Clay and Platte Counties, Inc: Gladstone
- The Arc of the Lake: Osage Beach
- The Arc of the Ozarks: Springfield
- The Arc of Missouri: Columbia

In July 2020, the National Recreation and Park Association, in partnership with the American Water Charitable Foundation, announced that they were awarding grant money to Franklin, Indiana, and Lawson, Missouri to develop water-inspired play areas. The city of Franklin will use the $250,000 grant to create the Amphitheater Splashpad in a downtown park that will be accessible to people with disabilities. The Splashpad "will create equal access to water play by being designed to accommodate those with mobility issues and other disabilities." The city of Lawson will create a similarly inclusive water splash pad for their community.[xxxvi]

The National Core Indicators (NCI) survey asks participants about community inclusion, participation, and leisure. Categories assessed include whether a person goes out for shopping, entertainment,

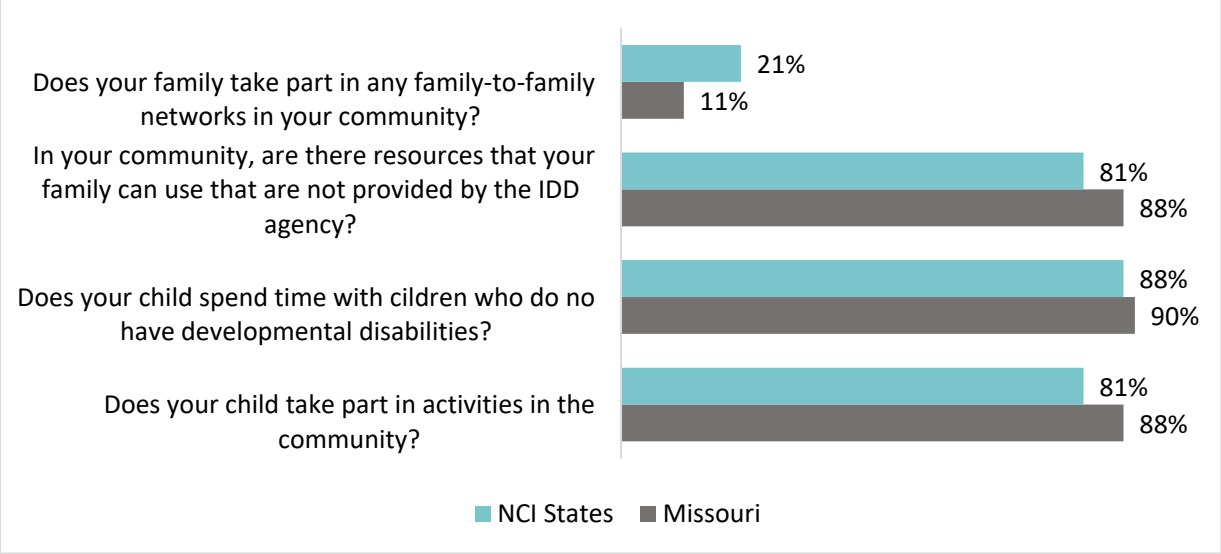
errands, food, or religious services, participates in community groups, and goes on vacation. For most categories, Missouri is in line with or slightly above the national average across NCI states. There were five categories in which Missouri's scores were lower than NCI states (Table 12): 1) went out for errands or appointments in the past month; 2) went out for entertainment in the past month; 3) participates as a member in a community group; 4) went on vacation in the past year and; 5) can be alone with friends or visitors at home.

Table 12. Community Inclusion, Participation, and Leisure, 2018-2019

Area Reported	Missouri	Across NCI States
Went out shopping in the past month	90%	89%
Went out on errands or for appointments in the past month	86%	87%
Out for entertainment in the past month	74%	77%
Went out to a restaurant or coffee shop at least once in the past month	89%	86%
Went out for a religious service or spiritual practice in the past month	42%	42%
Participates as a member in a community group	30%	34%
Went on vacation in the past year	42%	46%
Able to go out and do things they like to do in the community	91%	84%
Gets to do things they like to do in the community as much as they want	82%	77%
Has enough things to do when at home	88%	85%
Gets help to learn new things	77%	75%
Can be alone with friends or visitors at home	83%	85%
Can use phone and internet when they want	90%	89%

NCI also collects data on children and the degree to which they are included in the community. Figure 6 provides information on community involvement by children with IDD in Missouri.

Figure 6. Involvement in the Community, 2018-2019



Caregivers cited "other factors" (43%), "stigma" (39%) and "cost" (31%) as the most significant barriers to getting their child to take part in activities in the community.[xxxvii]

Despite efforts to involve people with IDD in the community, results from the Needs Assessment survey indicate that there is room for improvement in social, leisure, and recreational opportunities.

One section of the survey asked participants about the activities that they do—whether that activity was important to them and if they had unmet needs related to that activity. Four of the top five categories identified as important by participants related to recreation and social activities (Table 13). These categories also had some of the highest levels of unmet need. Listening session participants discussed the importance of socializing regularly, and the difficulties of doing so, particularly during the pandemic.

"It's always been important whether or not people spend their days doing meaningful activities, whether that be employment, pre-employment, school, volunteering, whatever it is that they're doing. But now, with COVID, it heightened that awareness about how difficult it is to achieve that--and it was already hard."

-Parent and Professional

Table 13. Importance and Unmet Need of Activities

Activity	Identified activity as important (%)	Identified as important AND had unmet need (%)
Social activities in your community	85.6	45.1
Friendships or relationships with others in your community	90.5	42.7
Leisure/hobby activities	91.0	37.2
Achieving personal goals	88.1	35.5
Parks and recreation activities	82.6	35.3

Other recreational activities of importance that were mentioned included clubs, camps and groups. Many family members and professionals reported a general dearth of opportunities for teens/young adults to socialize, as most programming targets children or is school-based. As children age, and particularly as they leave the school system, many of the structures that support socialization, recreation and engagement drop off, leaving families to scramble to fill in the gaps. Another concern is finding opportunities that are appropriate for a range of needs and disabilities. One parent noted, "One of the things that I found since my son is now an adult, is most of the adult programs are geared for people who like to do adult things. But my son is basically at a primary, or sometimes preschool, level. There are very, very, very few adult programs that target people at a lower level than adult…there's been problems finding recreational activities or programs that are of interest to him because of his age."

Despite the current challenges to accessing recreational activities, this was an important topic for listening session participants. Having opportunities to meaningfully engage socially and recreationally was one of the most frequently mentioned themes for people with IDD across the life course. One parent described the importance of engagement by saying, "That's what quality of life is--it's not just your job, but it's when you come home and you can say, hey, I want to go out to a movie with somebody or come over and I'll fix you dinner or whatever…I think that's where we have a big void."

Key Points

- There are several initiatives and organizations that are working to improve the state of recreational opportunities for Missourians with IDD. The type and quantity of these opportunities vary by region.
- Out of the 14 Community Inclusion, Participation, and Leisure indicators measured by the NCI survey, Missouri is at or above the NCI-state average in nine.
- While 88% of children in Missouri with a developmental disability were active in the community, only 11% of families that had children with disabilities engaged in family-to-family networks.
- Between a third and a half of surveyed Missourians indicated that they had unmet needs in areas related to socialization, relationship building, hobbies, personal goal achievement, and recreational activities.

TRANSPORTATION

Transportation is a critical component of accessing employment, healthcare, social engagements, recreational activities, and increased independence. As in past years, transportation continues to be a significant challenge for individuals and families with IDD in Missouri.

About 97% of NCI respondents in Missouri indicated that they have a way to get places they need to go and 92% have a way to get places when they want to do something outside the home. However, approximately 97% of NCI survey respondents cited lack of transportation as a reason that they cannot see their friends when they want.[xxxviii] This indicates that while there are transportation options available, there are still gaps in service.

Transportation is a concern for many families, particularly those living in more rural areas. The State of Missouri Disability Portal identifies the following resources as options for accessible transportation in Missouri. These suggestions vary in cost, eligibility and accessibility:

- Ability Transportation
- Accessible taxis (St. Louis)
- Cape Girardeau County Transit Authority
- Columbia Transit
- Direct Transit, a subsidiary of Ray County Transportation
- Jefftran - Jefferson City
- Joplin Transportation
- Metro - Kansas City
- Metro Transit - St. Louis
- OATS
- Segways
- Southeast Missouri Transportation Service
- Springfield Transit
- St. Charles County Transportation
- St. Joseph Transit
- West Plains Transit System[xxxix]

There are other transportation options that are regional or focus on specific populations, such as the Non-Emergency Medical Transportation program. This program provides free transportation to appointments with Medicaid-covered providers to those who lack access to free transportation through another source. Through NEMT, enrollees can schedule a ride to and from their medical appointments in advance. The service uses taxis, vans, public transit and more to help MO HealthNet recipients access their appointments efficiently and consistently.[xl] In 2017, the Non-Emergency Medical Transportation program made an average of more than 330,000 trips each quarter.[xli]

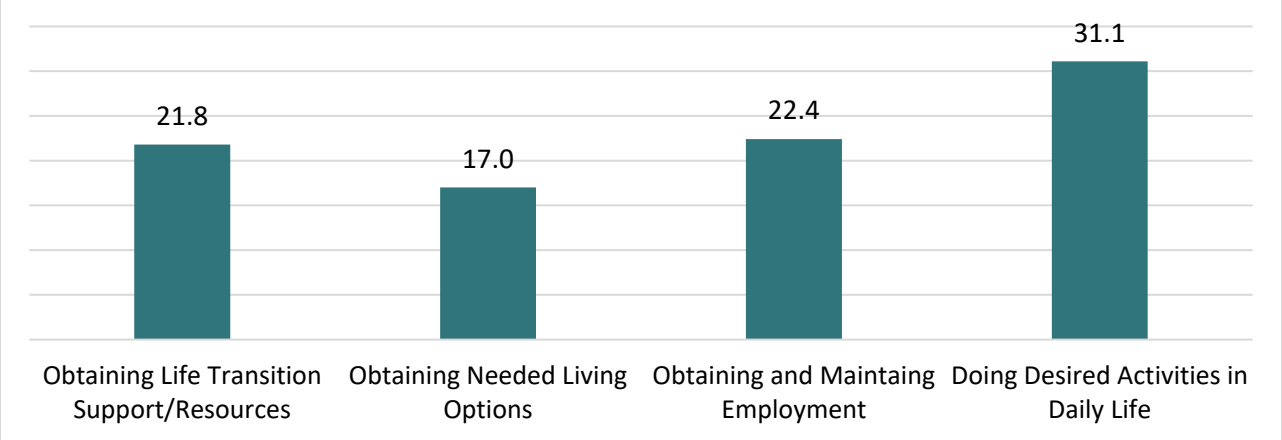
Another program is the Rides to Health and Wealth Network, which is currently in development for rural parts of the state. In 2019, the West Central Missouri Community Action Agency received a $100,000 grant from HRSA to implement Rides to Health and Wealth, which will use the HealthTran platform to help connect Missourians in rural areas to transportation options. HealthTran is a service in South Central Missouri that specializes in connecting rural patients to transportation options so they can access health care. The Rides to Health and Wealth program will be executed in partnership with the Missouri Rural Health Association and initial rollout of the program will be focused on nine rural counties.[xlii]

A 2019 study conducted by the Missouri Public Transit Association found that Missouri's 34 transit providers provide an average of 60.1 million rides a year. St. Louis and Kansas City have the most transportation options available, but every county in the state has some transportation service. Although 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 is very low and the state ranks 47th in the U.S. for state funding of transit.[xliii]

- Missouri's funding for transit ranks **47th** in the U.S.
- Missouri spends only **34 cents** per capita on transit
  - Illinois spends **$190** per capita

Respondents of the Needs Assessment survey identified transportation as a major barrier to living the life they would like to live. Nearly a third of respondents (31%) indicated that transportation issues made it difficult for them to find/keep employment and one in five participants noted that it prevented them from doing activities they wanted to do in their daily lives or from obtaining supports around life transitions (Figure 7). For 17% of respondents, transportation impacted their living situation. It was a particularly significant challenge for those living outside of urban centers.

Figure 7. Identified Transportation as a Barrier by Area of Daily Living (%)



Listening session participants spoke about the lack of reliable, affordable, and accessible transportation options. Issues such as inconvenient schedules, inopportune placing of bus stops, restrictive scheduling requirements, and difficulty affording services like Lyft or Uber were all mentioned. In an era of COVID-19, participants also stated that they did not always feel safe using public transportation or ride-share services. Participants from more rural areas pointed out that a lack of transportation options makes it difficult for them to access basic needs (grocery store, doctor's office, places of employment), but it also severely limits their ability to access amenities or services, to be independent and engage with their friends or community fully. One provider in rural Missouri said, "I've been working on transportation for three years, it's that needed. And it's not even in my job description."

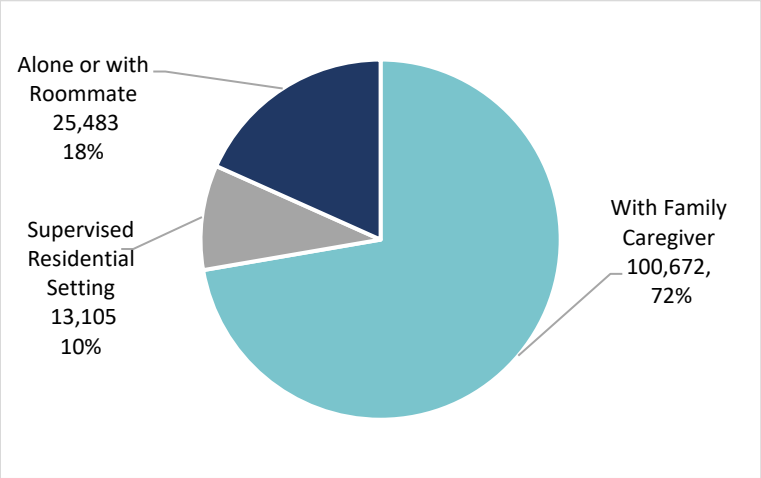
Key Points

- Accessible, affordable, and reliable means of transportation continues to be a challenge in Missouri, particularly for those in rural areas. A limited number of new transportation options have surfaced recently with a focus on connecting people in rural areas to health care.
- Despite the social and financial importance of Missouri's public transit system, transportation in the state lacks funding.
- A lack of transportation options impedes people's ability to access necessary resources, enjoy a full social life, and live with independence.

HOUSING

Safe, affordable, and accessible housing is key to enjoying a high quality of life. According to the U.S. Census Bureau, from 2014-2018, the median price of rent in Missouri was $809 a month.[xliv] Those who spend more than 30% of their monthly household income on housing are considered cost burdened. In Missouri, 28.7% of all households fall into this category, though rates vary by county, age, and homeowner/renter status.[xlv] In Missouri, 24% of all extremely low-income (defined as a less than $25,100/year income for a 4-person household) renter households include a person with a disability.[xlvi]

Figure 8. Estimated Number of Individuals with IDD by Living Arrangement, 2017



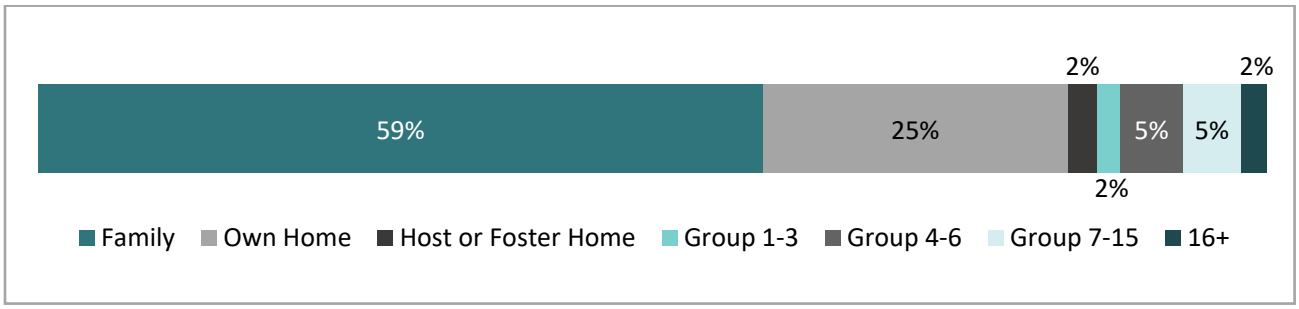
The majority (63%) of Missourians with a disability live in a metropolitan setting. Approximately 7% live in a rural area, 16% in a small town and 14% in a micropolitan area (residential designations defined by the USDA).[xlvii] The State of the States report data shows that in 2017, 72% of people with IDD in Missouri were living with their family, while 18% lived alone or with a roommate and 10% lived in a supervised residential setting (Figure 7). The majority of people living with family caregivers (39%) were under the age of 40 (Figure 8).[xlviii]

Among the population surveyed by NCI In-Person Survey, most people with an IDD live in their own home or apartment (46%), or in the home of their parents or another relative (32%). Nationally, only

18% of people with disabilities live in their own home/apartment and 38% live with family. In Missouri, about 3% live in foster care or a host home and 16% live in a group living setting of under 15 people. Only 1% of Missourians with IDD live in a nursing facility and less than 1% live in other ICF, IDD, or other specialized institutional facilities.[xlix]

The breakdown of residence type differs for those receiving LTSS through an IDD agency. In 2017, nearly 60% of LTSS recipients were living with their families and 25% were living in their own home (Figure 9). Approximately 12% were living in a group setting with 15 people or less and 2% were in a group setting with 16 or more people. Host homes or foster homes housed 2% of the LTSS population.[l]

Figure 9. Living Arrangements of LTSS Recipients in Missouri, 2017



NCI data also indicates that Missouri has higher rankings than the NCI states in categories related to satisfaction with living situations (Table 14). Compared to other NCI states, Missouri ranks particularly high in the category assessing if the person with IDD had input in choosing their housemates (59% in MO compared to 47% across states).[li]

Table 14. Choice of and Satisfaction with Living Arrangements, NCI 2018-2019

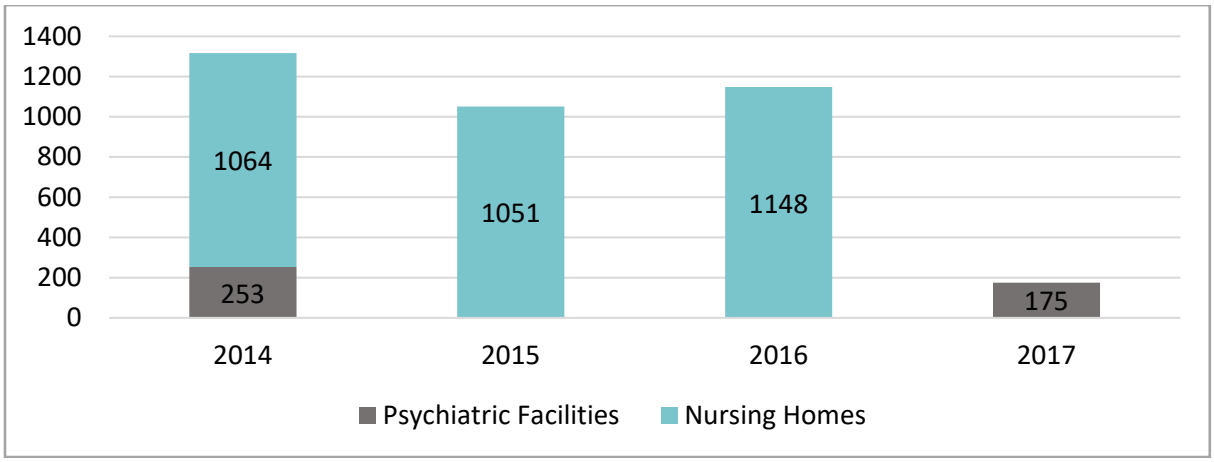
	Missouri	Across NCI States
Chose or had some input in choosing where they live if not living in the family home	61%	58%
Chose or had some input in choosing their housemates if not living in the family home, or chose to live alone	59%	47%
Like their home	94%	90%
Want to live somewhere else	19%	25%

Nursing facilities provide care when services cannot be provided in a community setting. Per the Missouri Department of Health & Senior Services, there are 1,165 long-term care facilities in the state. This equals more than 81,100 licensed beds, which are inspected by the state. Of these, 504 are skilled nursing facilities (SNF), 24 are intermediate care facilities (ICF), 369 are residential care facilities (RCF), and 268 are assisted living facilities (ALF).[lii]

In general, Missouri has been moving away from large group institutional residences for people with IDD, though data from the Residential Information Systems Project is inconclusive regarding the number of people with IDD living in nursing homes and psychiatric facilities over the past several years. The most recent data available is from 2017 and was only available for psychiatric facilities. Data for nursing

homes has remained around 1100 individuals for several years and the number of people in psychiatric facilities declined by about 75 people between 2014 and 2017 (Figure 10).

Figure 10. People with IDD in Nursing Home and Psychiatric Facilities, 2014-2017



As mentioned, Habilitation Centers are no longer an option for residential placement in Missouri. Individuals not currently residing in these facilities are admitted for short-term crisis stabilization only.[liii]

Nearly 70% of Needs Assessment respondents currently live with family. Among the respondents who identified living with family as important to them, 92% reported their needs were met. Minority respondents were more likely to identify living with family as important and were more likely to have their needs met than white, non-Hispanic respondents ($p<.05$). Minority respondents were also more likely to find living in a group home or supervised residential setting important (43.9% compared to 34.6% of white, non-Hispanic respondents) and more likely to anticipate needing more information about this topic in the next five years ($p<.05$).

Proportionally, those who identified other living situations (not with family) as important had much higher levels of unmet needs. Just over 50% of those who identified living independently without supports as important had unmet needs, as did 47% of those who identified living in a home with supports or living in a group setting as important. There was also a proportionally high level of unmet need among respondents who noted that living in a nursing or institutional care facility was important to them (45%).

Barriers to accessing desired living supports included a lack of knowledge of what is available (23%), cost (21%), and transportation (17%). Both survey respondents and listening session participants extrapolated on these topics. Financial concerns ("too expensive to live on my own") were shared by several respondents. Various other housing-related matters came up as well. Several people mentioned the difficulty of finding the necessary supports to live independently in the community. Many felt that they did not have the direct support staff needed to allow independent living. Others acknowledged the difficulty of finding accessible housing and how differential or discriminatory treatment of people with IDD could affect their housing experiences. Suggestions for improvement in housing options and living situations included landlord education and more options for home modifications.

Safety and privacy were also issues that were of high importance to Missouri's IDD community. Notably, 14% of respondents indicated that their needs around community safety were not met and 10% had unmet needs around feeling safe in their home. Although most respondents feel safe in their home or community, it is worth learning more about the experiences of the 10-15% who do not. One respondent wrote, "Finding an affordable home in a safe neighborhood" was challenging and listening session participants agreed. Several discussions included comments about how the housing stock that is affordable is often substandard or in places that felt unsafe to participants. Additional information on this topic can be found in the section discussing Victimization Prevention.

Housing Supports and Services in Missouri

There are several agencies in Missouri that offer housing and housing supports to people with disabilities.

The Missouri Inclusive Housing Development Corporation is a not-for-profit organization that assists individuals in finding safe, affordable, quality housing. The organization receives funding from MODDC and Missouri Department of Mental Health-Developmental Disabilities Division.

The Missouri Housing Development Commission assists with and funds the construction of affordable housing and provides funding for home loans to qualified, first-time buyers. The Commission administers several housing assistance programs including Missouri Low-Income Housing Tax Credit (LIHTC) programs, the Affordable Housing Assistance Program Tax Credit (AHAP) and federal HOME funds. It also directly funds several housing assistance programs and homeless assistance funds. The Commission also offers advice, consults, training, and educational services to non-profit housing organizations.[liv]

Missouri's Public Housing Agencies offer Low-Rent and Section 8 housing voucher options to qualified individuals. The Section 8 Housing Choice Voucher program helps older adults, individuals with lower incomes, and individuals with disabilities in finding affordable housing.

Assistance with Rental, Owning, and Modifying Residence

The mission of the Department of Mental Health's Housing Unit is to assist Missourians with disabilities "in obtaining and maintaining safe, decent, and affordable housing options that best meet their individual and family needs. The DMH Housing Unit believes that housing is a key to helping Missourians with disabilities and their families attain self-determination and independent living."[lv]

There are 2 programs offered through DMH's Housing Unit: Rental Assistance Program and Housing Development. Rental Assistance, a state-funded housing assistance program that offers one-time assistance to help prevent eviction and/or help households move to safe and affordable housing. The Housing Development program offers technical assistance for agencies seeking to develop affordable and/or supportive housing for Missourians either with or without disabilities.

Key Points

- Access to safe, affordable and accessible housing continues to be a concern for many Missourians with IDD and their families. The housing options available to a person depend on the level of support needed and support services.
- Most people with IDD live in their own home or in the home of a family member. Institutional settings are becoming less common, though small group settings remain an option for many.

- The majority NCI survey respondents (94%) reported liking their home, 61% chose or had input in where they live (if they were not living in the family home).

CHILDCARE

Missouri's DHSS provides childcare assistance for children with special needs in the form of referral services, technical assistance, and training. Services are administered through United4Children, which employs inclusion specialists to help families navigate their options and educate childcare providers. The childcare referral services help families identify and choose childcare that meets their needs. United4Children's inclusion specialists also provide technical assistance to families of children with special needs and regulated childcare providers. Finally, inclusions specialists also offer face to face training for childcare providers.

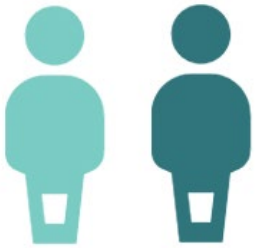
Missouri also offers an Early Head Start program which is a child development program available to children age 3 and younger who meet income eligibility guidelines. Early Head Start focuses on providing opportunities to promote children's physical, cognitive, social and emotional development and support parents and guardians. It also seeks to increase the quality and capacity of childcare programs and provides ongoing support to enrolled families.[lvi]

In community Listening Sessions, childcare was a frequently discussed issue. Families reported difficulty finding trusted and reliable before- and after-school care options. Participants described challenges finding childcare providers that are appropriately trained to support the needs of children with disabilities, and some expressed concern around potential abuse or neglect. Affordability was another concern for families. Inadequate access to childcare causes considerable stress for some families and in some cases, parents had to stop working to provide care.

The pandemic has brought childcare issues to the forefront, as more children are attending school virtually and more parents are working from home. Parents and caregivers reported an increased strain around balancing their own jobs and supervising their children at home. One service provider said, "I can tell you that in the last six weeks the primary phone call that I'm getting is families looking for daycare or in-home assistance for people who are now in virtual education program."

Responses to the Needs Assessment also indicate that adequate childcare is an unmet need for many families in Missouri. Approximately 29% of participants indicated that childcare was an important issue to them and about 15% of all respondents have unmet needs related to childcare. This means that overall, half of the people who identified that childcare is important to them do not have their childcare needs met. When asked about anticipated needs in the next five years, 16% cited childcare as an area in which they would need additional assistance or resources.

Further, when thinking about the next five years, nearly half of those identifying as a minority thought that before- and after-school care would be an important issue, and nearly half of them (24% overall) reported that they will need more information or resources. This is significantly different from responses of white, non-Hispanic participants, where only 13% indicated they will need additional resources on this topic in the next five years.



Half of Missouri families who reported that childcare is important to them have an unmet childcare need

INTERAGENCY INITIATIVES*

The MODDC is engaged in numerous initiatives in partnership with other agencies and organizations in Missouri to support capacity building and coordination efforts to improve the lives of people with IDD in the state. In addition to the partnerships listed below (and throughout this document), representatives from MODDC also are involved in other, more informal activities. For example, MODDC provides and pursues expertise through community meetings, listening sessions, community trainings, and advocacy efforts.

MODDC supports People First of Missouri, a statewide organization that promotes equality for people with disabilities and supports its members to self-direct and help each other. PFMO has more than 20 local self-advocacy groups across the state and each chapter works to fulfill the organization's mission to support self-advocacy, advocacy for one another, community advocacy, and systems-level advocacy.

MODDC also funds the First Responders Disability Awareness Training grant which provides in-person and virtual education on developmental disabilities to first responders and law enforcement professionals. Members of MODDC have presented to the Police Officer Standard Training Commission, EMTs, 9-1-1 Dispatchers and Law Enforcement. Despite the pandemic, these disability awareness trainings and train-the-trainer events are continuing to be held virtually to educate first responders.

This year, MODDC worked with various agencies and DD Councils from other states to develop and disseminate resources and tools in response to the COVID-19 pandemic. These resources include, but are not limited to:

- Instructions on how to use Zoom (English/Spanish)
- FAQ's on face coverings in plain language
- Documents with COVID-19 testing sites
- Emergency Preparedness Virtual Workshop for the Faith Community

MODDC also serves as a leader in the field of emergency preparedness for people with disabilities and other access and functional needs. As such, it works alongside other agencies to provide technical assistance to emergency management and public health communities on multiple topics. MODDC shares information and provides educational opportunities about emergency preparedness in the community, including sharing resources such as Mid-America Regional Council's *Your Very Personal Preparedness Inventory* and the Department of Homeland Security's *2020 National Preparedness Report*. The latter provides data on risk, hazards, and strategies around emergency preparedness. In 2019, Missouri had two disaster declarations, both related to severe storms, flooding and tornadoes/wind events. In 2020, Missouri had another two disaster declarations: COVID-19 and severe storms/flooding/tornado/wind events.

Members of MODDC also serve on the Access and Functional Needs Committee, which convenes leaders and representatives from a variety of agencies and organizations to identify gaps, barriers, and solutions to better support people with disabilities across the state.

The Family-to-Family Network (which includes the Family-to-Family Resource Center and the Sharing Our Strengths mentoring program) also receives support and input from MODDC. The Family-to-Family Network links individuals, families, and stakeholders to information and advocacy resources across the

state. Through mutual support and advocacy skills, the network seeks to support people with IDD and their families.

MO-WINGS is an interdisciplinary network of stakeholders in Missouri that focuses on issues surrounding guardianship, conservatorship and supported-decision making. The stakeholders include family members of those with disabilities, public administrators, service providers, members of advocacy organizations, government representatives and more. MODDC is a leading member of this group.

MODDC is also a part of the National Community of Practice, which supports families of individuals with IDD across the country. As a mentor state, Missouri assists five other states as they develop infrastructure to support families across the lifespan.

To address the high rates of victimization among people with IDD, MODDC created the Victimization Task Force. The task force seeks to prevent and address sexual, physical, and financial victimization of people with IDD through work group meetings, completing action items, and disseminating information at community and professional meetings. Current task force members include advocates, family members, People First of Missouri, Department of Health and Senior Services, Department of Mental Health, Missouri Protection & Advocacy, University Missouri Kansas City, Attorney General's Office, Department of Justice, Department of Elementary and Secondary Education, Missouri Secretary of State's Office, Federal Bureau of Investigation, Medicaid Fraud Control Unit, SB40 Boards, and more.

Missouri's federally designated UCEDD is the University of Missouri-Kansas City Institute for Human Development (UMKC-IHD). A group of advisors serve on the UCEDD Advisory Leadership Team (UCEDD-ALT) and this group includes MODDC, Missouri Protection and Advocacy, Missouri Assistive Technology, and Senate Bill 40 Boards, among others. Recently, UCEDD-ALT convened over 100 stakeholders to identify guiding principles, focus areas, and action steps to put supported-decision making into practice.

MODDC is a member of the Living Well Grant Leadership Team which includes partners such as MO Division of Developmental Disabilities, UMKC-IHD, People First of MO, MO Protection and Advocacy, MACDDS, MO Family-to-Family, Human Service Research Institute, National Community of Practice on Supporting Families, and National Association of State Directors of DD Services. The goal of the Living Well project is to build a model of community monitoring and capacity building that aligns with HCBS requirements.

Throughout FY2019, MODDC partnered with various entities to address housing issues for people with IDD, behavioral health issues, and dual diagnoses. Collaborators and referral network partners included HUD, Metropolitan St. Louis Equal Housing and Opportunity Council, MACDDS, Centers for Independent Living, Missouri Association of Rehabilitation Facilities, DMH, hospitals, Missouri Protection and Advocacy, and more. Housing density restrictions that impact residents with IDD were a focus of recent activities, but the wider purpose of MO Housing is to provide support, education and referrals to better understand, articulate and address Fair Housing Act violations occurring in Missouri.

MODDC also actively contributes to the Lay Education Advocacy Project (LEAP), a three-year project to develop a sustainable statewide program to equip family members, self-advocates and community members with skills, information, and support to advocate for inclusive education for people with IDD. The project will involve developing information, training, and peer support infrastructure that can

support individuals and families for years. Additional partners on this project include Missouri Family-to-Family, UMKC-IHD, Family Advocacy and Community Training, Legal Services of Eastern Missouri, and Missouri Protection and Advocacy.

In Missouri, there are 22 Centers for Independent Living (CILs) that offer independent living services. CILs offer five core services (peer counseling, advocacy, information and referral, independent living skills training, and services that facilitate with transitions into the community). They also can provide legal, housing, transportation, and education services. CILs operate from an Independent Living Philosophy and a CIL Board of Directors is required to have representation from the entire service catchment area and at least 51% of its members must be people with disabilities.[lvii]

There are 14 Workforce Investment Boards in Missouri that serve different regions of the state.[lviii] These boards are supported by the Workforce Innovation Opportunity Act of 2014 and provide resources and programming to support Missouri's workforce. Board representatives are required to be at least 51% business representatives and there is a focus on having member from a variety of organizations and fields.[lix]

The State Rehabilitation Council (SRC) was authorized by the Rehabilitation Act of 1973 and Missouri's Council was formed in 1993. Council members are required to represent a variety of fields, including disability advocacy groups, and members are appointed by the governor to three-year terms. The Council works in partnership with Missouri Vocational Rehabilitation to achieve positive outcomes for people with disabilities. In 2019 The SRC reported that through VR programming, 25,408 individuals worked with VR counselors and 4,396 achieved successful employment outcomes. Nearly 1,400 employed individuals received supported employment services and over 500 received Individual Placement and Support services. Of those served, 10% had Autism, 12% had IDD, 8% had a Specific Learning Disability, and 2% had a Traumatic Brain Injury. Three quarters of those with successful employment outcomes in 2019 were White, 20% were African American, and 3% were Hispanic.[lx]

In FY 2020, 55.4% of VR clients achieved employment after receiving VR services and results of VR's 2020 Customer Satisfaction Survey indicated high levels of satisfaction with the program. More than 95% of clients said that VR staff were available to assist them and that they were treated with courtesy and respect. Over 90% of clients noted that VR counselors explained their choices to them and helped them plan for the appropriate services.[lxi]

QUALITY ASSURANCE

Case for Inclusion Report: In its Case for Inclusion Report, the United Cerebral Palsy Foundation and the American Network of Community Options and Resources rank each state on their outcomes for individuals with IDD. In 2019, Missouri was ranked #4 out of all 50 states. While this is a slight drop from its #3 position in 2015, it is a substantial increase from its 2007 ranking of #41. Because of the significant advancement in outcomes for individuals with IDD in Missouri in the past decade, it is considered one of the nation's most-improved states. The Case for Inclusion report analyzes and ranks states in several domains: independence, health, safety and quality of

Case for Inclusion Rankings, 2019

- **#4 Health, Safety & Quality of Life**
- **#10 Keeping Families Together**
- **#13 Reaching Those in Need**
- **#18 Promoting Independence**
- **#20 Promoting Productivity**

life, keeping families together, productivity, and reaching those in need.[lxii] Missouri received its highest ranking (#4) in Health, Safety, and Quality of Life and its lowest ranking (#20) in Promoting Productivity.

Partners in Policymaking: MODDC's Partners in Policymaking is a leadership training program for adults with disabilities and parents of children with disabilities. The popular program seeks to build productive partnerships between those who need and use IDD services and those who hold influence. Participants learn leadership skills and strategies to partner with elected officials, school personnel, and others.

Quality Advisory Council: The Quality Advisory Council is a group of self-advocates, family members and organization representatives who meet to provide input and make recommendations to the Division of Developmental Disabilities (DDD). Their work focuses on the creation, development, and enhancement of the quality management system in DDD services. The QAC meets quarterly and includes representatives from MODDC, People First, Missouri Parents ACT, the Arc, Missouri Head Injury Council, Independent Living Centers and more.

CMS DDD TCM Policy Updates: In July 2018, the Centers for Medicare and Medicaid Services approved changes to the Division of Developmental Disabilities Targeted Case Management policies. The revisions impact TCM case manager qualifications and conflict free requirements. Per the staff qualifications requirements, case managers must have either a RN license or a bachelor's degree from an accredited institution. It also assures that "the provision of case management services will not restrict an individual's free choice of providers," allowing eligible individuals free choice of qualified Medicaid providers and preventing them from choosing the same entity to provide case management and waiver services.[lxiii]

The Missouri Crisis Intervention Team Council: This council is a state-wide network that provides education and advocates for policies that support community health and wellness by training law enforcement to de-escalate situations that involve a mental or behavioral health concern. They currently have three initiatives: The First Responder Provider Network, the Emergency Room Enhancement Initiative, and the Community Mental Health Liaisons Initiative.

Incident Reporting: The Missouri Department of Mental Health has a system for reporting and recording critical incidents and other incidents so they can be further investigated. DMH employees are responsible for completing, processing, reviewing and taking action on incident reports. The following list contains the incidents that are classified as critical and are therefore required to be reported:

1. Death of a consumer suspected to be other than natural causes;
2. Serious injury to a consumer;
3. Death or serious injury to a visitor at department state operated facilities;
4. Death or serious injury to a department employee or volunteer while on duty;
5. Serious incident of abuse/neglect, including abuse/neglect involving death, serious injury and sexual abuse;
6. Suicide attempt resulting in an injury requiring medical intervention (greater than minor first aid);
7. Elopement with law enforcement contacted or involved;
8. Criminal activity reported to law enforcement involving consumer as perpetrator or victim when the activity occurs at a facility. If not at a facility, then the criminal activity is serious (felony, etc.);
9. Fire, theft, or natural disaster resulting in extensive property damage, loss or disruption of service in department state operated facilities; and

10. Any significant incident the facility head district administrator, district deputy, chief executive officer or designee decides needs to be reported.[lxiv]

MO-WINGS: This is an interdisciplinary network of stakeholders in Missouri that focus on issues surrounding guardianship, conservatorship and supported-decision making. Stakeholders include family members of those with disabilities, public administrators, service providers, members of advocacy organizations, government representatives and more.

Legislative Education Project: The Governor's Council on Disability and the Missouri Statewide Independent Living Council collaborate on the LEP, which educates and motivates individuals about positive policy changes for people with disabilities. New to LEP are online learning modules and videos to teach people about the legislative process.

Missouri Youth Leadership Forum: The Forum is an annual career leadership training program for youth with disabilities age 16-21. The Forum is typically held in July. Due to the coronavirus pandemic, the 2020 session was cancelled, and four 1-day regional trainings are scheduled to be held in spring 2021.

Missouri Parents Act (MPACT): Funded by the U.S. Department of Education and the State of Missouri, MPACT is Missouri's Parent Training and Information Center. Their mission is to empower families to advocate so that children with special educational needs can reach their full potential in education and life.

VICTIMIZATION PREVENTION

Recent efforts of the MODDC emphasize preventing the victimization of people with IDD. The following initiatives describe some of these efforts and relevant data collected through the Needs Assessment survey and Listening Sessions, which highlight the ongoing need for this work.

It's Happening Campaign: In 2016, the Arc of Missouri received a grant from MODDC to raise awareness around the victimization of people with IDD. As part of this grant, they launched the "It's Happening" IDD Victimization Awareness Campaign which sought to educate the public about the signs of verbal, fiscal, physical, and sexual abuse. As part of the campaign, a website was launched with educational materials, stories, statistics, resources, and information on how to report abuse. Some material is available in both English and Spanish.

Abuse, Neglect and Exploitation Hotline: Missouri has a hotline to report Adult Abuse, Neglect and Exploitation of the Elderly and Disabled that is open 365 days a year from 7am to 12am. Reports can also be made to this hotline using an online form. The Missouri Department of Health and Senior Services operates this hotline and investigates abuse, neglect and exploitation of vulnerable populations, including people with disabilities between the ages of 18 and 59. The hotline responds to reports whether the individual is living in the community or in a long-term care facility.

Victimization Task Force: As mentioned, MODDC created a Victimization Task Force that focuses on issues related to the sexual, physical, and fiscal victimization of people with IDD. The task force brings together advocates, families, and representatives from a variety of agencies (People First of Missouri, DHSS, DMH, Missouri Protection and Advocacy, UMKC-IHD, Attorney General's Office, and more) to participate in work groups, take action, and give presentations at community and professional meetings.

Findings from the Needs Assessment survey showed that for Individuals, families, and professionals, victimization is never far from mind. They often spoke about victimization using language related to safety and trust, particularly related to caregivers providing childcare, day program care, and respite. One parent shared, "We've chosen not to send [child] to a day program or anything like that because we're really concerned about the fact that she's so vulnerable…I know the abuse and neglect that occurs with people that can't tell you about abuse and neglect."

Another concern that has surfaced during the pandemic is that virtual learning decreases the contact between students and school personnel, making it more difficult to identify safety concerns. Teachers and school staff are skilled at identifying and reporting concerns, but the lack of interaction and direct contact with students complicates the process of recognizing potential cases of victimization or neglect. One professional noted this dynamic: "A lot of times the teachers are the ones who find that victimization of the children. But the calls to that hotline have decreased significantly—by at least 50%." Another commented, "I think it's much more difficult to find those kinds of issues, particularly when things are virtual…you don't have the face-to-face contact with the families or children that we used to."

The topic of victimization and safety also came up in relation to housing. As previously discussed, some participants expressed that they did not feel comfortable with the housing they could afford, either because of the quality of the housing or their sense of safety in the community. One participant with an IDD commented, "I found some apartments that are not really safe for people to live because they do a lot of drugs in those areas." In fact, a full 10% of survey respondents reported that they do not feel safe in their home and 14% said they do not feel safe in their community. The percent of respondents who feel safe in their homes was very similar for Hispanic/Latinx and non- Hispanic/Latinx respondents, but there was a notable difference related to feeling safe in the community. About 12% of non- Hispanic/Latinx respondents reported that they had unmet needs related to feeling a sense of safety in community, while 26% of Hispanic/Latinx respondents had unmet needs around a sense of community safety.

1 in 4 Hispanic/ Latinx respondents have unmet needs related to feeling safe in their community

Several participants noted that education for families and individuals with IDD is important for preventing abuse and victimization. One parent credited the Partners in Policymaking class for opening her eyes to victimization issues among people with disabilities. Another parent in a listening session identified ongoing education as important to stopping incidents of victimization, "It would also be important to me, about sexual abuse, that there are workshops or something that we can take—either the parents or the teenagers themselves—about how to take care of ourselves and how to avoid being abused by someone else" (translated from Spanish).

HEALTH/HEALTHCARE

Access to Health and Mental Health Care

National Core Indicators data provide detailed information on people with IDD and health-related topics in Missouri and across the U.S. Table 15 contains data from the 2018-2019 NCI Missouri State Report. 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. However, Missourians were less likely to have had a recent

hearing test, more likely to have never had a colorectal cancer screening, and less likely to have a behavior plan.[lxv]

Table 15. 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%
Has a behavior plan	7%	23%
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%

In Missouri, 71% of respondents indicated that their family member with IDD can see health professionals when needed, which is 7% lower than the average for NCI states (78%). Missouri also lagged with dentist access—63% in Missouri indicated that their family member always goes to the dentist when needed while 68% did nationwide. Satisfaction rates with health care providers understanding the needs of people with IDD were lower in Missouri than across NCI states (Figure 11). Survey responses suggest that although most people feel that the needs of their family member with IDD are understood by medical providers, there

Figure 11. Healthcare Providers' Understanding of IDD

Family member's primary care doctor always understands your family member's needs related to his/her disability:	
MO	63%
NCI States	68%
Family member's dentist always understands your family member's needs related to his/her disability:	
MO	58%
NCI States	65%
For family members that use mental health services, the mental health professional always understands your family member's needs related to his/her disability:	
MO	57%
NCI States	62%

is room for improvement.[lxvi] This was particularly true for mental health professionals and dental care providers (57% and 58% respectively).

Results from UMKC-IHD's community data collection indicate that many families have an unmet need for behavior supports. A need for more access to behavior therapies, particularly ABA was mentioned by many parents during the listening sessions. In the Needs Assessment Survey, one in every five respondents reported that their needs around Behavioral Supports were not met. This was also the case when families were asked to anticipate their needs over the next five years; about half of respondents thought Behavioral Supports would be important to them and 26% indicated that they will need

additional resources. There were also statistically significant differences in the responses of Hispanic/Latinx and non-Hispanic/Latinx survey participants, where Hispanic/Latinx participants are more likely to find Behavioral Supports important, and more likely to have unmet needs related to these supports, both now and in the next five years ($p<.05$).

When asked about access to medical supports and services in the next five years, nearly 90% of survey respondents thought this topic would be important to them. More non-minority respondents thought that this topic was important than minority, but significantly more minority respondents reported that they would need additional information or resources on this topic in coming years ($p<.05$).

Identifying qualified providers and services was a challenge for some families. One parent commented, "what I'm hearing a lot about from the community is the lack of providers…the amount of providers that can provide care can be very slim. So providers, specifically in mental health arenas--so psychologists, psychiatrists--are hard to come by, especially for young children." This issue was exacerbated for families living in rural areas. Some parents reported driving several hours (or even to neighboring states) to receive medical supports and services for their child.

Maternal and Child Health Care

The National Survey of Children's Health (Title V Maternal and Child Health Services Block Grant Measures) measures a variety of indicators to understand the state of child and maternal health and healthcare in the U.S. It offers insight into access to health-related screening, treatments, and supports, some related to IDD. In 2017-2018, 32.7% of parents in Missouri completed a developmental screening for their child between the ages of 9 through 35 months. This is slightly below the national screening rate of 33.5%. More importantly, this means that two-thirds of children in this age range are not completing developmental screenings.

Similarly, 37.1% of parents with a child age 0-5 reported that their child's health care providers had asked if they had concerns about their child's learning, development, or behavior in the past year. This is above the national average (32.8%), but still indicates that most parents of young children (over 60%) are not being regularly asked about their child's behavior and development in a healthcare setting.[lxvii]

Nearly 7% of children in Missouri currently receive special services (such as speech, occupational, or behavioral therapies) to meet their developmental needs. This is in line with the national average of 7.6%. Of those children, 19.5% started services when they were under the age of three, 38.8% began to receive services between 3-5 and 41.6% did not receive services until they were six or older.[lxviii]

In general, access to preventative medical care in Missouri is in line with the United States, with about seven out of every ten children having had a preventative check-up in the past year (Figure 12). For preventative dental care (including check-ups, cleanings, sealants, and more), Missouri lags behind the United States by about 7%.[lxix]

Figure 12. Preventative Health among Children in Missouri and U.S.

	Had a preventative check-up in the last 12 months	Did NOT have a preventative check-up in the last 12 months
Missouri	70.3%	29.7%
Nation	70.7%	29.3%
	Received preventative dental care in the last 12 months	**Did NOT receive preventative dental care in the last 12 months**
Missouri	72.3%	27.7%
Nation	79.1%	20.9%

For the past 30 years, the United Health Foundation has ranked states across health-related topics and outcomes. In 2020, Missouri ranked #38. The ranking is based on indicators related to social and economic factors, the physical environment, clinical care, behaviors, and health outcomes. Missouri's highest ranking was for physical environment (25th) and its lowest ranking was for behaviors (43rd). The top three challenges identified by the report were low prevalence of exercise, high residential segregation, and low immunization coverage among children. Missouri's strengths were low prevalence of Adverse Childhood Experiences, high high-school graduation rate, and low prevalence of non-medical drug use. Missouri ranked 33rd for low birthweight and 46th for racial gaps in low birthweight.[lxx]

Based on clinical care data, Missouri ranks in the bottom half of states when it comes to availability of dentists (#40) and mental health providers (#36). Missouri also has a particularly low rating for public health funding (#44), spending just $57 per person. Alaska, the top-rated state in this category spends $281 per person. Public health spending is important because it allows states to be proactive in improving health and preventing poor health outcomes. Effective public health interventions can positively impact all members of society.[lxxi]

Services for Children with Special Health Care Needs

According to the Missouri Department of Health and Senior Services, "Individuals with special health care needs are those who have or are at increased risk for a disease, defect or medical condition that may hinder the achievement of normal physical growth and development and who also require health and related services of a type or amount beyond that required by individuals generally."[lxxii] Based on this definition, Missouri DHSS administers the Children and Youth with Special Health Care Needs (CYSHCN) Program, which provides service coordination and funding for medically necessary diagnostic treatment services for children meeting eligibility criteria.

In 2017-2018, approximately 293,652 Missouri children under the age of 18 had special health care needs. This prevalence rate (21.2%) is slightly higher than the national prevalence rate of children with special health care needs (18.5%). Of the 21.2% of children with SHCN in Missouri, 13.3% had more complex health needs and 7.9% had less complex health needs. Approximately 51% of the children with SPHN meet medical home criteria. [lxxiii]

The 2017-2018 National Survey of Children's Health indicated that the number of CYSHCN in Missouri varied by subpopulations. For example, males were more likely have special health care needs than females (25% for males vs. 17.6% for females). Non-Hispanic Black children experience the highest

prevalence of special healthcare needs (40.8%) followed by White, non-Hispanic children (19.0%) then Hispanic children (18.9%).

In Missouri, there are several programs developed specifically to meet the needs of CYSCHN. Descriptions of the programs are below:

- **Healthy Children and Youth Program** – "The HCY Program provides service coordination and authorization for medically necessary services for MO HealthNet recipients with special health care needs from birth to age 21. Service coordination includes assessment through home visits and links to services and resources that enable participants to remain safely in their homes with their families. Authorized services may include in-home personal care, in-home nursing care and skilled-nursing visits."[lxxiv]

- **Family Partnership for Children & Youth with SHCN** – "The Family Partnership provides resource information and peer support to families of children and youth with special health care needs. Families are also given the opportunity to network with each other through various settings, including regional and statewide meetings. The Family Partnership includes individuals with special health care needs as well as their parents, legal guardians or siblings. SHCN utilizes information from the Family Partnership to enhance the relationship among SHCN and the individuals and families it serves. The Family Partnership employs four professional Family Partners. Family Partners are parents of individuals with special health care needs and provide information and peer support to family members. In addition to assisting families, the Family Partners plan, schedule and facilitate all Family Partnership events."[lxxv]

- **Children and Youth with Special Health Care Needs Program** – "The CYSHCN Program provides assistance statewide for children and youth with special health care needs from birth to age 21. The program focuses on early identification and service coordination for children and youth who meet medical eligibility guidelines. As payer of last resort, the program provides limited funding for medically necessary diagnostic and treatment services for children whose families also meet financial eligibility guidelines."[lxxvi]

- **The Medically Fragile Adult Waiver** – "The Medically Fragile Adult Waiver (MFAW) Program provides service coordination and authorization for medically necessary services to MO HealthNet recipients with serious and complex medical needs who have reached the age of 21 and are no longer eligible to receive services through the Healthy Children and Youth (HCY) Program. Participants must require medical care equivalent to the level of care received in an intermediate care facility, not be enrolled in another waiver and have been eligible for private duty nursing through the HCY Program. Authorized services may include in-home personal care, in-home nursing care, skilled nursing visits, supplies and equipment."[lxxvii]

Children's Mental Health Services

Missouri's Department of Mental Health provides several programs and services for Missourians with mental illness and IDD. Descriptions of these programs and services from Missouri DMH's website can be found below: [lxxviii]

Outpatient Community-Based Services

Outpatient services provided to a person in their community. Services are provided by a team that uses the resources of the individual, his/her family, and the community. Outpatient programs offer individual, group, and family therapy, medication management, etc.

Targeted Case Management

Targeted Case Management services are used to assist individuals in finding and getting psychiatric, medical, social, and educational services and supports.

Day Treatment/Partial Hospitalization

Day treatment offers care to individuals diagnosed as having a psychiatric disorder and requiring a level of care greater than outpatient services can provide, but not at a level requiring full-time services in a hospital. The focus is on developing supportive medical and psychological and social work services. Day treatment may include rehabilitation services, educational services and vocational education.

Residential Services

Residential Services provide a variety of housing alternatives to meet the diverse needs of individuals. The Department of Mental Health assists Missourians challenged by mental illness in obtaining and maintaining safe, decent and affordable housing options that best meet their individual and family needs. Housing is a key to helping Missourians with disabilities and their families attain independent living. The vision of the Department is that all Missourians challenged by mental illnesses have housing options that are affordable and accessible, integrated into communities, and provide real choice.

Inpatient (Hospitalization)

Individuals whose psychiatric needs cannot be met in the community and who require 24-hour observation and treatment are placed in inpatient treatment. These services are considered appropriate for persons who may be dangerous to themselves or others as a result of their mental disorder. Children with Serious Emotional Disturbances or in acute crisis may receive the above-mentioned services as well as services provided through the programs listed below.

Respite

Temporary care given to an individual by specialized, trained providers for the purpose of providing a period of relief to the primary care givers.

Treatment Family Home Program

This service provides individualized treatment within a community-based family environment with specially trained parents. It allows out-of-home services for those needing them, but also allows children to remain in their own communities and often in their home school districts.

Community Psychiatric Rehabilitation (CPRP)

This program is a person-centered approach that emphasizes individual choices and needs; features flexible community-based services and supports; uses existing community resources and natural support systems; and promotes independence and the pursuit of meaningful living, working, learning, and leisure-time activities in normal community settings. The program provides an array of key services to persons with severe, disabling mental illnesses. Services include evaluations, crisis intervention, community support, medication management, and psychosocial rehabilitation. Because CPRP is a

Medicaid supported program, the federal government pays approximately 60 percent of the costs for eligible clients.

Participants in the Needs Assessment survey and listening sessions indicated that accessing appropriate mental health services in a timely manner was often a struggle for them. They cited long wait lists and a lack of providers in their area (particularly psychologists and psychiatrists who work with children) as major factors that prevented their families from accessing mental health services. One professional also discussed challenges of providing mental health care that is appropriately tailored to the IDD population, particularly when services are needed in Spanish.

Insurance Access

An important component of health care access is health insurance. In Missouri, there are four options available: Medicaid (MO HealthNet), Medicare, the federally facilitated insurance plans and employer-based coverage. 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.[lxxix] The federal marketplace also assesses applicants' Medicaid/CHIP eligibility, then transfers the account to the state agency for a final eligibility determination.

In August 2020, Missourians voted in favor of Missouri Constitutional Amendment 2, the Medicaid Expansion Initiative. The passage of this amendment expands MO HealthNet services to more people and makes Missouri the 38th state to approve Medicaid expansion through the Affordable Care Act. It is estimated that when the expansion goes into effect, it will allow 230,000 low-income Missourians to access Medicaid. Missouri is required to expand MO HealthNet by July 2021. Many of the details of the program and its rollout remain unknown, but it is likely to increase health insurance access for many low-income Missourians.[lxxx]

Across age groups, most Missourians with a disability receive their health insurance through public health insurance programs. Adults with disabilities between 19-64 years old have the highest rates of being uninsured, with 12% lacking health insurance entirely. Table 16 contains additional information about insurance coverage by age for Missourians with a disability.

Table 16. Insurance Coverage for Missourians with Disabilities[lxxxi]

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%

The majority (65%) of nonelderly Medicaid recipients were white, 22% were Black and 5% were multiple races (Table 17). Approximately 7% identified as Hispanic.

Table 17. Distribution of the Nonelderly Medicaid Population by Race/Ethnicity, 2019 [lxxxii]	
Race	**Percent**
White	65%
Black	22%
Hispanic	7%
Asian/Native Hawaiian and Pacific Islander	1%
American Indian/Alaska Native	1%
Multiple Races	5%

During FY2020, the number of enrollees in MO HealthNet grew by nearly 60,000. In July 2019, there were just under 599,000 Missourian enrolled and by June 2020, there were over 657,000 people in the program. Nearly 95% of those enrolled were part of the 1915(b) Managed Care waiver, while just over 5% were part of the Children's Health Insurance Program (CHIP).[lxxxiii] Approximately 156,000, or about 16% of the people enrolled in MO HealthNet qualify for services because of a physical or mental disability.[lxxxiv] In July 2020, there were 957,280 people enrolled in MO HealthNet; 166,352 of those enrollees (17%) were people with disabilities.[lxxxv]

Health care costs for people with disabilities were the highest of the four populations served by MO HealthNet (older adults, people with disabilities, children, and non-disabled adults 19-64, Table 18). The average cost for an enrollee with disabilities was $2,315 per month, which is substantially higher than any other group.[lxxxvi]

Table 18. Annual MO HealthNet Expenditures by Population and Individual per Month Costs, 2018			
	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

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 language (English, Spanish, Bosnian, and Vietnamese).

Health insurance was a topic that was mentioned multiple times during listening sessions. Families recounted the difficulties they had finding providers in their network and getting coverage for needed services. Some providers also commented on trends they have seen with health insurance, "we see families' insurance getting more restrictive, not only in covering certain types of equipment, but increased deductibles and co-pays." Participants in the Spanish language listening session also noted that health insurance is not always accessible, or families are not always comfortable applying due to immigration-related concerns, limiting their access to funded services.

Prevention and Wellness Initiatives

MO HealthNet Primary Care Health Home initiative provides care coordination and care management for the medically complex population (defined as Medicaid participants with two or more chronic health conditions, including developmental disabilities). This initiative emphasizes the social determinants of

health and integrated primary and behavioral health care to improve health outcomes. The MO HealthNet PCHH network partners with over 40 organizations and over 160 clinics.[lxxxvii]

The Behavioral Support Review Committee promotes best practices through "peer review, education, and consultation."[lxxxviii] The statewide committee is run by Missouri's DDD and provides consultation to ensure best practice standards are met, the least restrictive strategies are utilized, and that Medicaid Waiver assurances are met. The committee also provides peer review to help find solutions to difficult situations, as well as provide networking and support. Technical assistance and training for providers on topics such as evidence-based strategies, data collection, and ethics are also offered.

The previously mentioned **Non-Emergency Medical Transportation** program provides free transportation services to Medicaid appointments to those who lack transportation. Rides are scheduled in advance and the program uses taxis, vans, public transit and other options to assist patients in accessing their appointments.

There are several 1915 Waiver Programs available through the Division of Developmental Disabilities[lxxxix]:

Comprehensive Waiver

To be eligible for the Comprehensive Waiver an individual must:

- Be eligible for Medicaid (otherwise known as MO HealthNet) as determined by Family Support Division (FSD) under an eligibility category that provides for Federal Financial Participation (FFP);
- Be determined by regional office to have a developmental disability as defined by Section 630.00-5(9), RSMo, (1994); and
- Be determined by the regional office initially and annually thereafter to require an ICF/IDD LOC.

Community Support Waiver

To be eligible for the Community Support Waiver an individual must:

- Be eligible for Medicaid (otherwise known as Mo HealthNet) as determined by FSD under an eligibility category that provides for FFP;
- Be determined by regional office to have a developmental disability as defined by Section 630.005(9), RSMo, (1994);
- Be determined by the regional office initially and annually thereafter to require an ICF/IDD LOC;
- Have needs that can be met within the waiver cap of $28,000 (this amount is adjusted annually by the consumer price index).

Missouri Children with Developmental Disabilities (MOCDD or Sarah Jian Lopez) Waiver

In order to be considered for participation in the MOCDD Waiver, the child must:

- Be eligible to receive Division of DD services (have a developmental disability as defined by Section 630.005(9), RSMo, (1994));
- Be living at home;
- Be under the age of 18; and
- Have a need for a waiver service;
- Not be eligible for any regular MO HealthNet programs;
- Require an ICF/IDD LOC and be at risk of entering an ICF/IDD facility if not provided services under the waiver.

- Be determined by the regional office initially and annually thereafter to require an ICF/IDD LOC.

It must also be determined:

- That maintaining the child at home rather than in placement, is both safe and economical (cost less than the equivalent LOC in an ICF/IDD).
- If other agencies (First Steps, local school districts) are serving or have primary responsibility for providing formal paid supports to the child; or
- If the child is eligible for other state plan MO HealthNet services (such as those provided under the Bureau of Special Health Care Needs (BSHCN) that would meet the child's needs). If these services do not meet the child's needs (provide an adequate level of services and/or the appropriate type of services), then waiver services may be considered.

Partnership for Hope Waiver

To be eligible for the PfH Waiver individuals must:

- Be a resident of a participating county upon enrollment and while receiving waiver services;
- Be eligible for Medicaid (otherwise known as MO HealthNet) as determined by FSD under an eligibility category that provides for FFP;
- Be determined by regional office to have a developmental disability as defined by Section 630.00 5(9), RSMo, (1994);
- Persons do not require residential services and typically are living in the community with family members;
- The individual is at risk of needing ICF/IDD institutional services if unable to access waiver services to subsidize care and support provided by the community and/or family;
- The estimated cost of waiver services and supports necessary to support the person must not exceed $12,362 annually.
- Be determined by the regional office initially and annually thereafter to require an ICF/IDD LOC.

Autism Spectrum Disorder Waiver

- This waiver recently expired and those needing ongoing services were transitioned to the Community Support Waiver.

Community Support Waiver[xc]

- For persons who live in the community (usually with family)
- Meet intermediate care facility for individuals with intellectual disability level of care
- Be at risk of needing ICF/ID services if waiver services not provided

Participation in waiver programs vary considerably. Table 19 shows the number of IDD waiver participants and expenditures based on 2018. [xci] Table 20 contains financial information for HCBS waivers from 2018.[xcii]

Table 19. 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

Table 20. Missouri's HCBS IDD Waiver Program Expenditures, 2018					
Waiver	**Target Population**	**FY 2017 Expenditures**	**FY 2018 Expenditures**	**FY 2019 Expenditures**	**Percent Change 2018-2019**
Comprehensive Waiver	IDD Including ASD	$108,247,242	$85,020,179	$61,342,856	-27%
Community Support Waiver	IDD Including ASD	$13,874,764	$13,771,848	$10,416,435	-1%
Autism Waiver	ASD-Children Only	$1,312,182			
Partnership for Hope Waiver	IDD Including ASD	$9,861,856	$5,228,747	$2,969,286	-89%
Children with IDD Waiver	IDD Including ASD-Children Only	$3,802,818	3,945,963	$4,394,780	4%

Healthcare for Culturally and Linguistically Diverse Populations

As mentioned, some families experienced greater challenges accessing healthcare 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. When asked about behavioral healthcare for their child, one parent noted, "You don't hardly have any Spanish speaking counselors or therapists." Additionally, access to telehealth appointments were identified as a challenge for Spanish-speaking families who are not comfortable navigating technology or do not have reliable internet access. Even in-person health appointments can be difficult if interpretation services are not dependable. These challenges are in addition to the immigration- related concerns some families have related to enrolling in Medicaid.

Families living in rural Missouri voiced similar concerns about accessing telehealth appointments. Broadband internet access and comfort using technology (both devices and software) present barriers to some families. The lack of options for providers and the distance that some families must travel to see healthcare providers is another challenge, particularly for families with children receiving regular therapies.

Long Term Services and Supports

An important set of programs offered relates to a continuum of services offered through Long Term Supports and Services (LTSS). These services can be provided in a variety of settings, including both institutional and community settings (Table 21). Residential Information Systems Project (RISP) data from the University of Minnesota finds that the majority of LTSS recipients receive services in their home. The most recent RISP data is from 2017 and estimates that there are about 19,120 people with IDD who receive LTSS in Missouri. The majority of Missouri's LTSS recipients (58%) were over the age of 22 while 42% were 21 or younger.[xciii]

Table 21. Residence of LTSS Recipients with IDD in 2016

Residence Type	Number	Percent of all LTSS Recipients
Family Home	10,922	58%
Own Home	4,558	24%
Host or Foster Home	414	2%
Group Setting (1-6)	1,450	8%
Group Setting (7-15)	490	5%
Group Setting (16+)	420	2%

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 106,000. 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 population.[xciv] Table 22 provides data on expenditures and participation in LTSS by setting and service.

Table 22. LTSS Spending by Service Category, FY2018[xcvi]					
	LTSS Service Category	Total LTSS Expenditure (in millions)	Percent of LTSS Expenditures	Average Participants (in thousands)	Percent of total LTSS Population
Institutional	Skill nursing facility	$1,041	36%	29.8	28%
	Intermediate care	$84	3%	0.4	0%
Waiver HCBS	Adult day care/ day habilitation	$182	6%	6.1	6%
	Career and financing	$10	0%	5.8	6%
	Community services	$5	0%	1.5	1%
	Counseling and therapy	$5	0%	1.2	1%
	Residential services	$661	23%	6.8	6%
	Personal care	$63	2%	3.4	3%
	Private duty nursing	$16	1%	0.2	0%
	Respite care	$4	0%	0.4	1%
	Targeted case management	$58	2%	13.3	13%
	LTSS other	$27	1%	15.0	14%
State plan HCBS	Personal care	$701	24%	61.7	58%
	Private duty nursing	$20	1%	0.3	0%
	Targeted case management	$9	0%	6.0	6%
Total		**$2,886M**		**105.2 participants**	

In recent years, Home and Community-Based Services have been more widely encouraged and used in 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 the states in the U.S (14.9%).[xcv] In 2019, 61% of Missouri's LTSS funds were used for HCBS, which is slightly above the national average of 57%. Although Missouri had 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. In fact, 24% of Missouri's nursing home residents have low care needs, compared to 11% national average. This indicates that there are potential opportunities to support these residents with HCBS rather than institutional care.

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. Each domain contains several different indicators and the scores are aggregated to rank the U.S. states.

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). While Missouri's performance did not decline in any areas, only two indicators saw improvement—Medicaid LTSS Balance: Spending and Person and Family Centered Care. Missouri's full report card can be found on the following page.

Missouri: 2020 Long-Term Services and Supports State Scorecard Data

Dimension and Indicator (Current Data Year)	Current Rate	Baseline Rate	Rank	Change	National Average	Top State Rate
OVERALL RANK			**30**			
Affordability and Access			**3**			
Nursing Home Cost (2018-19)	**168%**	170%	**1**	▬	245%	168%
Home Care Cost (2018-19)	**84%**	80%	**30**	▬	80%	51%
Long-Term Care Insurance (2018)	**55**	60	**11**	▬	43	138
Low-Income PWD with Medicaid (2016-18)	**50.2%**	50.0%	**37**	▬	56.7%	79.2%
PWD with Medicaid LTSS (2017)	**61**	57	**7**	▬	46	100
ADRC/NWD Functions (2019)	**82%**	81%	**15**	▬	66%	96%
Choice of Setting and Provider			**12**			
Medicaid LTSS Balance: Spending (2016)	**42.7%**	39.3%	**18**	✔	45.1%	73.5%
Medicaid LTSS Balance: Users (2017)	**65.2%**	63.8%	**18**	▬	64.2%	83.9%
Self-Direction (2019)	**47.2**	*	**7**	*	30.4	149.1
Home Health Aide Supply (2016-18)	**23**	22	**17**	▬	22	47
Assisted Living Supply (2016)	**43**	49	**29**	▬	49	102
Adult Day Services Supply (2016)	**44**	44	**20**	▬	61	171
Subsidized Housing Opportunities (2017-18)	**6.2%**	6.0%	**19**	▬	6.2%	18.6%
Quality of Life and Quality of Care			**48**			
PWD Rate of Employment (2016-18)	**18.9%**	18.8%	**41**	▬	21.4%	38.1%
Nursing Home Residents with Pressure Sores (2018)	**7.9%**	*	**35**	*	7.3%	4.8%
Nursing Home Antipsychotic Use (2018)	**18.8%**	19.4%	**49**	▬	14.6%	7.8%
HCBS Quality Benchmarking (2015-19)	**1.2**	*	**24**	*	1.30	3.60
Support for Family Caregivers			**39**			
Supporting Working Family Caregivers (6 policies)	**0**	0	**38**	▬	3.17	13.50
Family Responsibility Protected Classification (2019)	**0**	0			0.29	2.00
Exceeds Federal FMLA (2019)	**0**	0			0.29	3.00
Paid Family Leave (2019)	**0**	0			0.50	3.50
Mandatory Paid Sick Days (2019)	**0**	0			0.85	3.00
Flexible Sick Days (2019)	**0**	0			0.75	3.00
Unemployment Insurance for Family Caregivers (2019)	**0**	0			0.49	1.00
Person- and Family-Centered Care (3 policies)	**2.80**	0.50	**31**	✔	3.04	5.50
Spousal Impoverishment Protections (2019)	**0.50**	0.50			0.90	2.00
Having Caregiver Assessment (2019)	**1.30**	0			1.34	2.50
CARE Act Legislation (2019)	**1.00**	0			0.80	1.00
Nurse Delegation and Scope of Practice (2 policies)	**4.00**	4.00	**23**	▬	3.30	5.00
Nursing Tasks Able to be Delegated (2019)	**4.00**	4.00			2.69	4.00
Nurse Practitioner Scope of Practice (2019)	**0**	0			0.61	1.00
Transportation Policies (1 policy)	**0**	0	**8**	▬	0.14	1.00
Volunteer Driver Protection (2019)	**0**	0			0.14	1.00
Effective Transitions			**48**			
Nursing Home Residents with Low Care Needs (2017)	**24.0%**	*	**49**	*	8.9%	2.1%
Home Health Hospital Admissions (2017)	**16.1%**	16.5%	**31**	▬	15.8%	13.8%
Nursing Home Hospital Admissions (2016)	**17.5%**	18.8%	**36**	▬	16.8%	4.7%
Burdensome Transitions (2016)	**27.7%**	27.6%	**35**	▬	28.6%	16.2%
Successful Discharge to Community (2017-18)	**50.0%**	*	**47**	*	53.9%	68.5%

* Comparable data not available for baseline and/or current year. Rank cannot be calculated without current data. Change in performance cannot be calculated without both baseline and current data.

ADRC/NWD = Aging and Disability Resource Center/No Wrong Door

CARE Act = Caregiver Advise, Record, Enable Act

FMLA = Family and Medical Leave Act

HCBS = Home- and Community-Based Services

LTSS = Long-Term Services and Supports

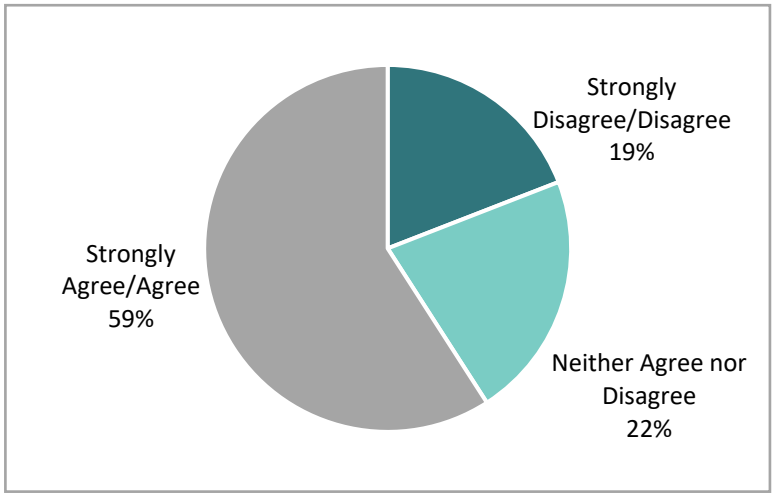
PWD = People with Disabilities

Key for Change:	
✔	Performance improvement
▬	Little or no change in performance
✖	Performance decline
*	No trend available

Emergency Preparedness

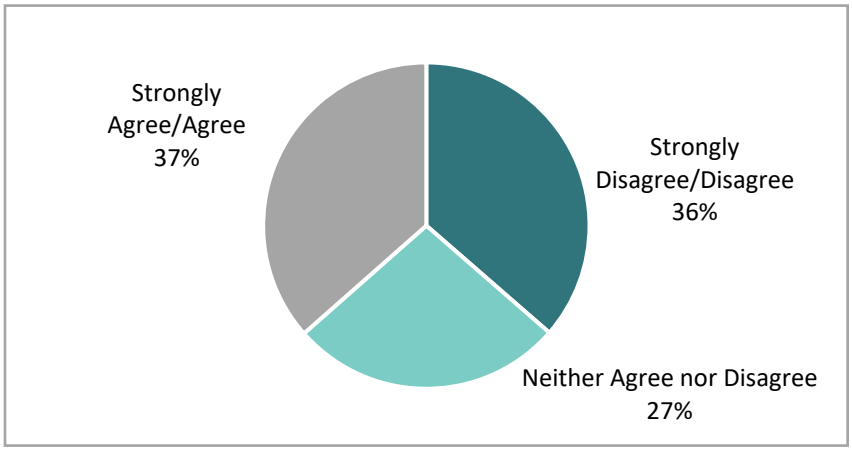
The Needs Assessment Survey explored participants' preparedness for future emergencies. Nearly 20% of respondents indicated that their family was not prepared for an emergency and an additional 22% were unsure if they were prepared or not (Figure 13). While most respondents (60%) agreed or strongly agreed that they were prepared, 40% were either unprepared or uncertain about their preparedness. In general, slightly more non-Hispanic/Latinx respondents felt prepared for an emergency than Hispanic/Latinx respondents (60% compared to 50%), though differences were not statistically significant.

Figure 13. My family is prepared for any type of emergency/ natural disaster



Over a third of respondents either agreed or strongly agreed that they need more information and/or resources related to emergency preparedness (Figure 14). Respondents who were members of a minority group were less likely to agree or strongly agree that they are prepared for an emergency (47%) than those who did not identify as minority (63%). They were also more likely to agree or strongly agree that they needed more information or resources on the topic (42% compared to 35%).

Figure 14. My family needs more info/resources on emergency preparedness



"I just want to see in the next five years that nothing like COVID-19 ever happens again. Are you prepared for what's going to happen? And knowing what we need to do and knowing what we're going to need can help us."

-Person with IDD

Key Points

- Missouri has strengths and weaknesses regarding access to and availability of preventative and treatment-based health care. One area of growth for Missouri is increasing developmental screenings in young children.
- Among Missourians with disabilities, the age group that has the highest rate of insurance coverage is people over 65 (100%). The age group that has the lowest rate of insurance coverage is 19-64 (88%). This may change in the coming year with the passage of Medicaid Expansion.
- The number of people enrolled in MO HealthNet is growing and currently, there are over 657,000 people receiving health insurance. About 16% of those enrolled have a physical or mental disability and people with disabilities have the highest cost per enrollee ($2,315 a month).
- There are several services available for Missourians with disabilities depending on their eligibility including CYSHCN services, Medicaid waiver programs, targeted case management, inpatient and outpatient mental health programs and more.
- The Comprehensive Waiver is the most utilized and accounts for the most expenditures.

EDUCATION/EARLY INTERVENTION

Since the 1989-1990 school year, Missouri's Department of Elementary and Secondary Education has been gathering data on special education students. In the 2019-2020 school year, there were 119,242 students ages 5K-21 receiving IDEA services. These students fall into the following categories:[xcvii]

- Intellectual Disability: 9,134
- Emotional Disturbance: 7,201
- Language Impairment: 8,427
- Speech Impairment: 17,032
- Orthopedic Impairment: 393
- Visual Impairment: 445
- Hearing Impairment: 1,051
- Specific Learning Disability: 31,338
- Other Health Impairment: 26,674
- Deaf/Blindness: 25
- Multiple Disabilities: 1,392
- Autism: 12,611
- Traumatic Brain Injury: 398
- Young Child with Developmental Delay: 3,121

Table 23 summarizes data from the U.S. Department of Education IDEA Data Center on children and youth receiving special education services by age, race, and disability category.

Table 23. Youth Served by Special Education in Missouri by Race/Ethnicity, 2017[xcviii]

SEA Disability Category	Age Range	Total	American Indian or Alaska Native	Asian	Black or African-American	Hispanic/ Latino	Native Hawaiian or Other Pacific Islander	Two or More Races	White
Autism	3-5	750	4	18	104	45	3	20	536
	6-21	11,474	46	262	1788	608	10	449	8311
Developmental Delay	3-5	10,500	33	214	1508	685	30	482	7548
	6-21	1,002	3	16	185	74	2	50	672
Intellectual Disability	3-5	158	0	2	22	5	0	8	121
	6-21	9,216	38	123	2614	480	12	245	5704

As part of the Individuals with Disabilities Education Improvement Act of 2004, Missouri is required to publicly report on the performance of each local education agency and develop a State Performance Plan (SPP). The SPP identifies student performance indicators and sets goals for targets to improve activities and experience for students with disabilities. Students with disabilities are defined as those who quality for special education services and have an Individualized Education Program (IEP). Assessment categories included Early Childhood Special Education, Child Count and Educational Environment, Assessment, Evaluation, Parent Survey, and Secondary Transition Data. Progress data on the SPP from the 2019-2020 school year was recently released and Missouri met 14 out of the 24 goals that were set. A full copy of the report, which contains various indicators related to special education services, can be found here: https://dese.mo.gov/sites/default/files/se-data-mo-state-profile.pdf. A copy of the State Performance Plan / Annual Performance Report can be found here: https://dese.mo.gov/sites/default/files/se-data-SPPAPR_PARTB_2018-19.pdf.

In the Needs Assessment and listening sessions, participants identified and defined several areas of development for schools. In general, respondents noted that there are barriers in the school setting for children with disabilities to get what they need. Staff are not always appropriately trained to work with children with disabilities and some parents described how their children are treated differently than their neurotypical peers. Some parents indicated that they felt that their child's education and learning was not taken as seriously as they would like. One participant shared that they are aware of a school in which students with IDD miss out on classroom lessons to serve coffee, a task that students without IDD do not do. Other parents noted that they did not always feel included in their child's education plan and that it was challenging to effectively advocate for an individual student's needs, especially when it came to IEPs. One respondent noted, "schools need to accept parents and student as equal partners in the IEP and be willing to listen for the benefit of the student."

As a result of COVID-19, challenges around education are even more pronounced. Families explained that when schools switched to online learning in spring 2020, they lost access to many school-based services and therapies. For some children, virtual learning was extremely difficult, and parents often did not feel that they had the proper support to help their child. This was especially true for those who were also juggling their own full-time work. Some described a lack of accommodations for special needs students during the pandemic and many parents noted that IEPs were not always honored.

Parents also expressed concerns about their children regressing in academic, social and life skills because of the changes in routine and education structure. One professional described the situation: "Families are concerned that the virtual format will leave their kids behind. In a lot of cases, they don't feel as though a virtual education is appropriate. There is concern that in order to engage in a virtual education, people need one on one support to make that happen within the family home…and families are really panicking. They don't know what to do. And there are very limited resources to be able to help them."

Some participants also noted that no entity takes the lead on assisting families with future planning for life transitions, and that schools might be a natural place to engage in this process. Planning across the lifecourse—but particularly planning for transitions such as leaving school or retiring from work—was an issue of consequence for many participants. Nearly a quarter of Needs Assessment respondents said they had unmet needs around planning for the transition from school to work or adult life, including 46% of Hispanic/Latinx participants. Schools were seen as underutilized resources for this type of

planning, and participants indicated that they would like their school system to assist with future planning. During Listening Sessions, several parents noted that there was a substantial drop-off of services, activities, and resources when their child left high school and they would have liked to have had a roadmap or guide in place at that time.

Unsurprisingly, guardianship was an important and commonly discussed aspect of future planning. While schools are often a resource for families considering guardianship, several participants explained that they did not feel like the school gave them a comprehensive explanation of their guardianship options. One parent said, "It was the school disctrict…they're the ones who push push push on the guardianship. But they don't tell you what the range of guardianship is."

> ***"The most common question we get at 18 is, 'How do I start guardianship?' They say how. People are just not aware that supported-decision making is an option. Oftentimes, they're not aware that no guardianship of any kind, or formal support of any kind is even needed in some instances."***
> ***-Parent and Professional***

Participants explained that they did not know where to find accurate and comprehensive guardianship-related information, especially in rural areas. This specific concern was explicitly voiced by some Hispanic/Latinx families who noted that there are gaps in guardianship support from the school and from other sources. Several participants reported that information is not always disseminated to Spanish-speaking populations in effective ways, "A lot of Latinx families, hardly any of them know that they are supposed to become guardians or apply for guardianship for all these services… I think we haven't done a good job in providing information enough to parents--information, that is culturally sensitive or culturally competent."

Key Points

- Learning Disabilities and Other Health Impaired are the most common disability categories among students receiving special education services in Missouri.
- Families and students with IDD are not always actively included in the IEP process. Many feel that the development of the IEP is not a collaborative process and unless they are consistently advocating, their child will have a subpar IEP.
- The coronavirus pandemic has presented challenges for students with IDD related to service/therapy provision and virtual learning. Schools and families are continuing to adapt.
- Families are seeking resources and guidance that will help them plan for their family member's future, including with the transition from school to work/adult life, guardianship, and retirement.

EMPLOYMENT

As discussed, in Missouri, people with disabilities had an employment rate of 36.1% in 2018. This is much lower than the 81.7% employment rate for people without disabilities. Employment rates for people with disabilities vary by type of disability. For example, people with a hearing disability were the most likely to be employed, while people with a self-care disability were the least likely to be employed. Employment rates also vary by geographic region. Within Missouri, Scotland county had the highest

employment rate for people with disabilities (59.0%), while Douglas county had the lowest (15.1%) (Figure 15).[xcix]

Figure 15. Employment Rate for Civilians with Disabilities Ages 18 to 64 Years Living in the Community

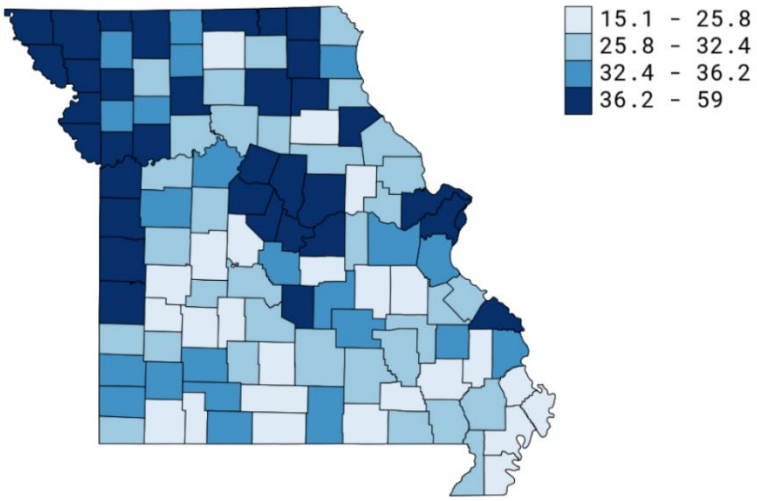


Table 24 displays employment status by disability type in Missouri over the past five years. In 2019, the number of people with a cognitive disability who were employed full-time year-round dropped from 32,476 in 2018 to 23,453. The number of people with a cognitive disability that did not work grew from 128,055 in 2018 to 132,642.

Table 24. Employment by Disability Type, 2015-2019[c]					
	2019	2018	2017	2016	2015
Total:	**363,0849**	**3,642,782**	**3,644,362**	**3,653,174**	**3,667,679**
Worked full-time, year-round:	**2,062,508**	**2,032,454**	**2,019,163**	**1,979,594**	**1,971,508**
With a disability:	**111,518**	**104,212**	**113,496**	**104,672**	**103,708**
With a hearing difficulty	35,808	33,154	36,980	34,841	36,982
With a vision difficulty	33,217	19,062	22,456	22,552	22,127
With a cognitive difficulty	23,453	32,476	31,035	28,165	25,621
With an ambulatory difficulty	34,183	31,769	36,050	34,553	35,908
With a self-care difficulty	7,022	5,513	5,812	4,777	5,256
With an independent living difficulty	15,646	13,887	15,347	12,125	11,527
No disability	1,950,990	1,928,242	1,905,667	1,874,922	1,867,800
Worked less than full-time, year-round:	**853,267**	**895,629**	**921,484**	**930,344**	**946,709**
With a disability:	**89,631**	**88,264**	**93,641**	**90,932**	**92,591**
With a hearing difficulty	17,142	18,326	19,903	16,692	17,310
With a vision difficulty	16,392	14,719	13,005	15,050	15,712
With a cognitive difficulty	43,409	42,664	47,645	40,663	44,573
With an ambulatory difficulty	31,729	32,423	33,220	34,929	32,915
With a self-care difficulty	9,206	10,256	9,384	8,011	7,659

Table 24. Employment by Disability Type, 2015-2019[c]					
	2019	2018	2017	2016	2015
With an independent living difficulty	26,909	26,604	27,525	24,960	24,099
No disability	763,636	807,365	827,843	839,412	854,118
Did not work:	**715,074**	**714,699**	**703,715**	**743,236**	**749,462**
With a disability:	**258,514**	**254,040**	**256,827**	**272,536**	**266,858**
With a hearing difficulty	37,038	38,886	36,366	41,506	38,161
With a vision difficulty	43,971	43,737	39,744	44,552	44,798
With a cognitive difficulty	132,642	128,055	128,274	137,925	133,235
With an ambulatory difficulty	156,864	155,201	159,433	170,160	168,075
With a self-care difficulty	66,119	63,162	58,790	61,234	63,313
With an independent living difficulty	135,806	128,268	124,859	127,234	126,187
No disability	456,560	460,659	446,888	470,700	482,604

Although the number of people with a cognitive disability who are employed full-time or less than full-time decreased between 2015-2019, data from the ACS indicate that the percentage of individuals with cognitive disabilities that are employed steadily increased between 2014 and 2017 (Table 25). In 2017, 28.7% of individuals with a cognitive disability were employed, which is approximately 5.5% more than in 2014.

Table 25. Percentage of Individuals with Disabilities Employed (aged 21 to 64) by Disability Type[ci]					
		2017	2016	2015	2014
Visual Disability	Missouri	39.9%	40.2%	37.6%	40.1%
	Nationwide	44.2%	43.7%	42.0%	40.4%
Hearing Disability	Missouri	54.2%	50.2%	51.2%	50.1%
	Nationwide	53.4%	52.1%	51.8%	51.2%
Ambulatory Disability	Missouri	23.7%	22.0%	22.8%	22.2%
	Nationwide	25.4%	24.9%	24.3%	24.2%
Cognitive Disability	Missouri	28.7%	24.9%	26.4%	23.2%
	Nationwide	27.9%	26.4%	25.5%	24.2%
Self-Care Disability	Missouri	14.5%	11.7%	11.1%	14.9%
	Nationwide	16.3%	15.4%	15.8%	15.5%
Independent Living Disability	Missouri	18.3%	15.9%	15.2%	15.8%
	Nationwide	17.8%	17.1%	16.3%	16.0%
Any Disability	Missouri	35.9%	34.2%	34.5%	32.9%
	Nationwide	37.3%	36.2%	35.2%	34.6%

Many people with disabilities are interested in Integrated Employment opportunities, though these opportunities can be difficult to find. In 2018, 15% of individuals participating in day or employment services were part of an integrated employment program (Table 26). This is below the national average of 21% participation, but it is an improvement from previous years.[cii]

Table 26. Number of Individuals Participating in Integrated Employment Services Provided by State IDD Agency[ciii]				
	Missouri (2018)		**Nationwide (2018)**	
	Number	**Percent**	**Number**	**Percent**
Total in day and employment services	6,276		641,608	
Total in integrated employment services	963	15%	135,228	21%
Total funding for day and employment services	$108,758,164		$9,376,286,593	

Total funding for integrated employment services	$6,976,280	6.4%	$891,362,403	12%

Supported employment programs are another option for people with disabilities. According to State of the States data, there were 6,228 participants in day/work and supported employment programs in 2017. Approximately 12% of these participants were engaged in the supported employment program. In FY 2017, expenditures on supported employment programs in Missouri accounted for less than 1% of total budget spending.[civ] Table 27 displays a snapshot of sheltered workshop participation in April 2019 and 2020. In FY2021, it is projected that sheltered workshop programs will serve about 6,000 people.[cv]

Table 27. Sheltered Workshop Participation, April 2020[cvi]

	Number of employees	**FTE**	**Hours worked**	**Wages Paid**	**Average hourly wage**
April 2020	5,625	4,320	447,685	$2,240,553	$5.00
April 2019	5,903	4,705	586,501	$2,641,399	$4.38

The 2019 MO State Rehabilitation Council Annual Report provides data on several employment outcomes. It reported that in 2018, 28,764 individuals worked with vocational rehabilitation counselors and 4,589 individuals had successful employment outcomes. Of this group, 10% had autism, 14% had an intellectual disability, 7% had a specific learning disability, and 2% had a traumatic brain injury. Just over 1,800 youths reached successful employment outcomes. Out of the successfully employed individuals in the VR program, 1,505 received supported employment services and 523 received Individual Placement and Support services. Seventy-seven percent of individuals served by VR were white, 18% were African American, 3% were Hispanic, 1% were American Indian and less than 1% identified as either Asian or Pacific Islander.[cvii]

According to the report, VR has made a strong effort in recent years to improve services for underserved populations. To meet this goal, they have employed the following strategies:

- Employment of a part-time disability consultant
- Regular meetings of the Cultural Diversity Team
- Cultural competency and diversity trainings for employees
- Appointment of an Autism Services Liaison
- Employment Services Plus Program (designed to assist those with ASD, TBI, or deafness/hearing loss)
- Two peer mentoring pre-employment transition pilot projects for students in the justice and foster care systems

In FY 2021, vocational rehabilitation services are projected to reach 28,000 individuals.[cviii]

The National Core Indicators survey gathers data on how adults with disabilities view their access to employment.[cix] It compares information on how adults with disabilities spend their days, the input they had in this decision, the type of work they do, and their satisfaction with their work. Missourians with disabilities are less likely than their peers in NCI states to attend a day program or sheltered workshop (46% compared to 56%, Table 28). Missourians are 5% less likely to report having a paid job in the

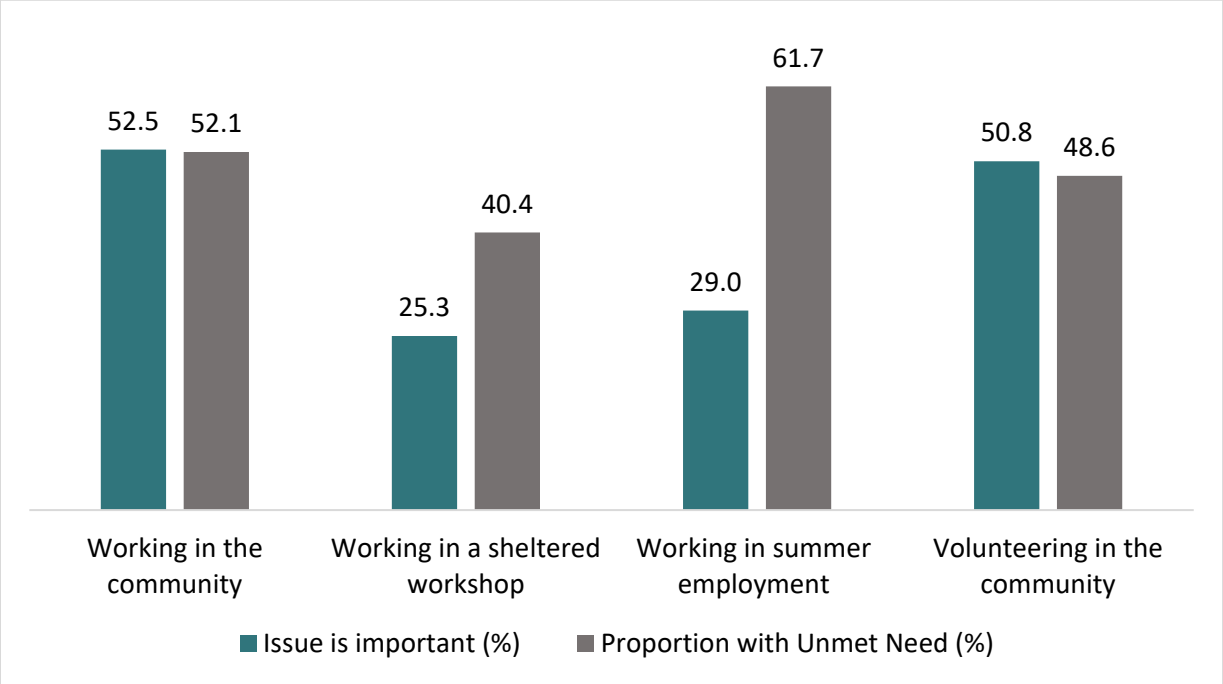
Table 28. Employment Data from NCI, Adult In Person Survey, 2018-2019

Area Reported	Missouri	Across NCI States
Chose or had some help in choosing paid community job	98%	89%
Chose or had some help in day program or workshop	68%	62%
Without a paid job in the community who would like a paid job	41%	44%
Have community employment as a goal in their service plan	20%	29%
Attend a day program or regular activity	46%	56%
Do volunteer work	28%	34%
Has a paid job in the community	14%	19%
Average Time at Job	50.4 months	69.6 months
Industry: Food preparation and service	45%	24%
Industry: Building or Grounds Maintenance	18%	28%
Industry: Retail	13%	21%
Industry: Assembly, manufacturing, or packaging	4%	8%
Received Paid Time Off	25%	29%

community (14% compared to 19% of those in NCI states). Respondents from NCI states reported an average length of employment of 69.6 months, which was 19.2 months longer than Missouri's average length of employment (50.4 months). Nearly all respondents with a paid community job in Missouri (98%) chose or had help in choosing where they work, which was 9% higher than NCI states. Most NCI respondents in Missouri with a community job (52%) do not receive publicly funded supports, while 35% do receive supports. Approximately 7% have a group job and 5% work in a community business that primarily hires people with disabilities. Data on the average number of hours worked and hourly wages were only available for jobs with publicly funded supports in Missouri, with individuals working an average of 37.5 hours every two weeks and receiving $9.59 per hour.[cx]

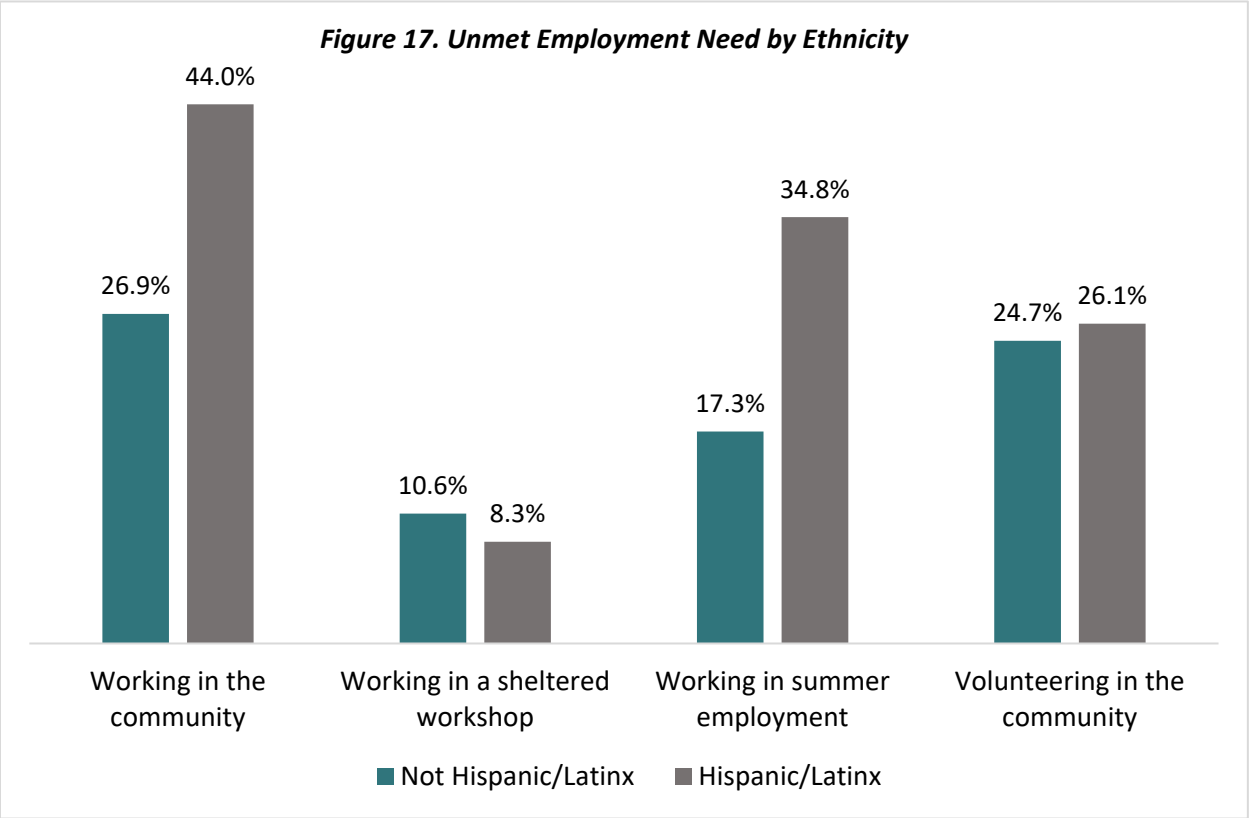
Findings from the Needs Assessment and listening sessions show that employment is an important aspect of life for many people with IDD, yet many have unmet needs in this area (Figure 16). Over half of survey respondents (52.5%) indicated that working in the community was important to them, though more than half of that group stated that they had unmet needs related to community employment. One challenge that was mentioned in the Listening Sessions is a difficulty identifying jobs in the community and/or getting adequate support through programs like the Workforce Innovation and Opportunity Act. One parent wondered, "Where do we go for jobs? For somebody who is looking for an entry level job that has a disability—I'm going to be frank with you, I'm not impressed." This was a particularly salient issue for individuals and families transitioning out of high school and into a work or volunteer setting.

Figure 16. Employment Importance and Unmet Need



Another employment-related theme that surfaced in both the Needs Assessment and the listening sessions related to employer education on hiring people with IDD. According to participants, a lack of awareness of the disability community and a dearth of available employment supports discourage employers from hiring and retaining employees with disabilities. Community education, partnerships with local employers, and increased awareness around disability are needed to create more opportunities for people with disabilities in the workforce. One person described what they had experienced when working to build partnerships between local employers and agencies serving those with IDD, “Talking to employers, while they didn't really have anything bad to say about working with people with disabilities, you could just tell that it was a different type of people that they may not be used to working with, and so they didn't understand how well it would work.”

Other work-related topics included summer employment, which was important to 29.0% of respondents and working in a sheltered workshop, which was important to 25.3% of respondents. The largest unmet need was seen in the summer employment category, where nearly 62% of respondents who thought this issue was important had unmet needs. Survey respondents who identified as Hispanic/Latinx had significantly different responses from those who identified as non-Hispanic/Latinx. Over 70% of non-Hispanic/Latinx respondents indicated that Summer Employment was not important to them and 17.3% said it was important, but their needs were not met. More than half of Hispanic/Latinx respondents identified this topic as important (52.2%) and 34.8% responded that it was important, but needs are not being met ($p<.05$, Figure 17).

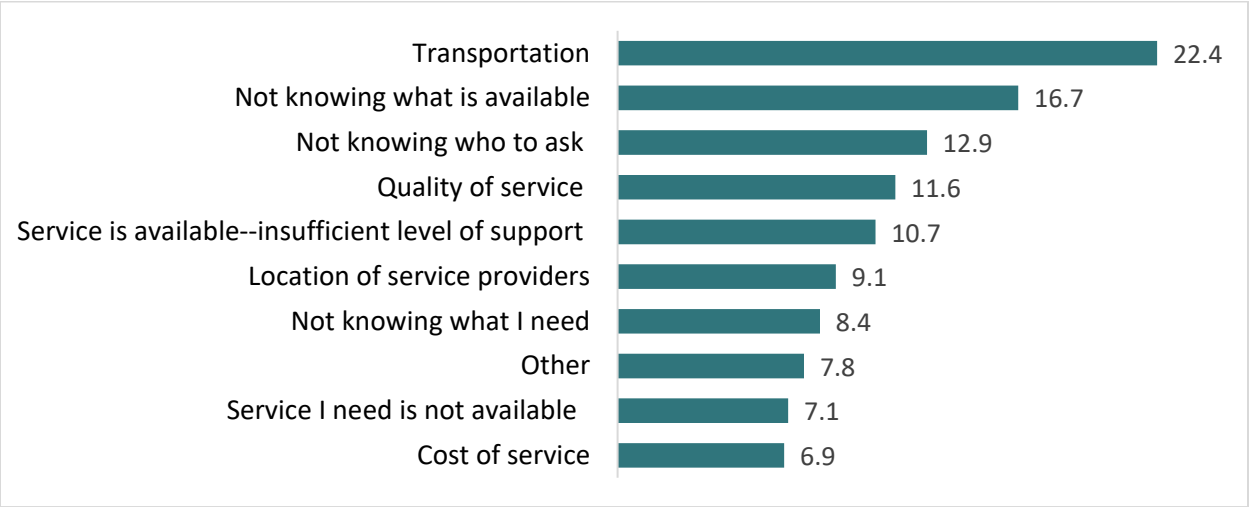


Similarly, when asked about what issues would be important in the next five years, Hispanic/Latinx respondents more often indicated that summer employment was important and that they will need additional resources ($p<.05$).

It was clear from Listening Sessions, that the pandemic has complicated the work situations of many people with IDD. Those that were working voiced concerns around potential exposure risk in the workplace, while others expressed disappointment that they are not able to go to work, "I miss working. I like to be able to work." Others miss the social connections they have at work, "I miss seeing my coworkers' smiling faces every day."

According to results from the Needs Assessment survey, the biggest barrier to accessing and keeping employment is transportation (nearly a quarter of respondents identified this as an obstacle). Not knowing what resources are available or who to ask to learn about resources presented additional obstacles (Figure 18). Availability of jobs was also mentioned in listening sessions as an obstacle to employment, particularly for participants in rural Missouri: "We have people that want to work, but we also have limited number of jobs available in our county."

Figure 18. Barriers to Finding and Keeping Employment (%) n=606



Job and Job Training Services

Aside from the employment programs already mentioned, several other services and resources exist for Missourians with disabilities in the workforce. The Workforce Innovation and Opportunity Act coordinates and streamlines VR services and cross-agency teams have been built to help improve the workforce system for all involved.

The Department of Mental Health created a DB101 resource, which is a Missouri-specific benefits planning website. It offers information to working individuals with disabilities including the impact of work on health care and other disability benefits.

Missouri also offers a Ticket to Work Health Assurance Program. The purpose of this program is to provide medical care for people with disabilities who are in the workforce. Eligibility is based on age and income guidelines.

The Missouri Chamber of Commerce and Industry offers Show-Me Careers, a 5-day professional development bootcamp delivered in regions across the state. The goal of the program is to expose students to various career paths by connecting school educators, counselors, and administrators with industries that have shortages.

For the past five years, several agencies in Missouri have collaborated to host an EmployAbility Inclusion event, which focuses on providing employers with information on the benefits of hiring individuals with disabilities. The host agencies have included VR, the Ozark Workforce Development Board, Missouri Job Center, CRPs, and the Springfield Human Resources, among others.

The need for a more robust job training or pre-employment training system came up numerous times during community data collection. One parent and professional said, “I think something that's in short supply in the state of Missouri, unfortunately, is access to pre-employment skills…everybody talks about pre-employment, but they're really not doing anything with it.” Participants also noted that there are few opportunities for people with IDD to explore career path options or truly engage in competitive integrative employment. A professional commented, “I would like to see more competitive employment

options and unique job training opportunities for people with disabilities, so that they have more choice in their employment options, more choice in how they're supported."

A final theme that is important to address in relation to employment and volunteering opportunities for people with IDD is the need for appropriately matched jobs or activities for the individual's skill level. One parent described the difficulties they had faced in finding a good job opportunity for their child with IDD who "wouldn't thrive in a [sheltered workshop], she's too advanced for something like that, but not advanced enough for other situations." Other participants, particularly those who had family members with multiple or complex disabilities, also had trouble finding appropriate work or volunteer opportunities to engage their loved ones. One parent said, "I couldn't find a volunteer position for [son] anywhere…. It has been hard to find a fit for somebody at his level that has multiple disabilities."

Employment Initiatives through Missouri DMH

Employment First: Employment First policies support community integrated employment services and supports as the first option and primary outcome for people with disabilities. They champion the idea that individual integrated employment is a preferable option for people with disabilities.

Employment First Missouri is a product of Missouri DMH and the Institute for Community Inclusion at the University of Massachusetts Boston. It provides no-cost technical assistance and trainings to service providers and other stakeholders to further community employment options for people with IDD.[cxi]

Missouri Employment First Collaborative brings together the Division of Developmental Disabilities, Division of Behavioral Health, Missouri HealthNet, Rehabilitation Services for the Blind, VR, and Workforce Development to support and enhance systems to help individuals meet their employment goals. The collaborative receives support from the Employment First State Leadership Mentoring Program and past activities have included:

- Scaling practices of Customized Employment - a flexible and mutually beneficial strategy for matching job seekers with businesses.
- Developing professional skills with benefits planning – planning to balance earned income with social security and health insurance benefits in effective way.
- State Agency Collaboration – creation of a multi-state agency Memorandum of Understanding on Employment First and public programs.
- Missouri as a Model Employer - an emerging idea that was developed by the National Governors Association. The goal is to help people with disabilities get competitive integrated employment by supporting the state government in hiring more people with disabilities.[cxii]

Empowering through Employment: In 2016, the Empowering through Employment Initiative was launched with the goal of growing the number of individuals interested in community-based employment. As of May 2020, the program was serving 1,055 individuals. Targeted Case Management agencies are evaluated by the percentage of individuals in their region with employment service authorizations. As of May 2020, 2 TCMs (6 county region) had over 35% of individuals with employment authorizations. Another 11 TCMs (18 county area) had between 25-34% of individuals with employment authorizations, and 36 TCMs (56 county area) had between 13-24%.[cxiii]

State Employment Leadership Network: This network is a national collaborative of more than 30 states, and Missouri's Division of Developmental Disabilities participates. The collaborative is sponsored

by the National Association of State Directors of Developmental Disabilities Services and the Institute for Community Inclusion out of the University of Massachusetts Boston. Its goal is to reinvigorate employment outcomes for people with IDD.[cxiv]

Key Points

- Employment rates among people with disabilities vary by geographic region and disability type though overall employment rates are lower for people with IDD than people without.
- The percent of people with a cognitive disability who were employed in Missouri rose to 29% in 2019, however, the raw numbers indicate that less people with cognitive disabilities are working full-time, year-round jobs.
- Missouri spends about 6% of its IDD funding on integrated employment programs, which is considerably less than the 12% national average. Nationally, 28% of people completing the NCI survey had integrated employment as a goal in their service plan, while only 20% of those in Missouri did. Together, this indicates that integrated employment has not been as highly prioritized in Missouri as in other states.
- Sheltered workshop programs attracted about 5,500 participants in Missouri in 2019, slightly less than in 2018.
- According to NCI data, 94% of respondents either chose or had input in where they work and 72% chose or had input in where they spend their days, suggesting that Missourians with IDD are often actively involved in their job or day program decision.

INFORMAL AND FORMAL SUPPORTS AND SERVICES

Not all Missourians live in an area where formal services for individuals and families with disabilities are easily accessible. Some Missourians use services and supports (both formal and informal) to support their quality of life. The 2017 State of the States report estimates that in 2017, only 5.8% of IDD caregiving families received support from state IDD agencies.[cxv] This is substantially lower than the national average of 10% and indicates that the majority of families who are providing care to a family member with IDD are not receiving support from state agencies. A report compiled by RISP estimates that there are approximately 36,850 people in Missouri who were served by the state's IDD agencies in 2017.[cxvi]

Several community support options are available to people with IDD and their families including support groups, peer supports, home and community-based services and efforts to empower and increase visibility of populations with IDD. One example of an initiative led by MODDC is the Coffee with Katheryne series. Coffee with Katheryne meetings are online listening sessions where people with IDD and their families can voice concerns, gather information and resources, hear from others in the IDD community, and share their ideas about how MODDC can advocate for them.

Another resource for families is the Family Advocacy and Community Training (FACT) DD Family Support Program. A recent evaluation of the program from St. Charles, MO indicates that participation significantly increased families' capacity to achieve a good life in three domains: informational support, emotional support, and goods and services. It also significantly decreased the urgency of family needs in nearly 80% of indicators.[cxvii]

In the Needs Assessment survey, more than 80% of respondents indicated that self-advocacy and self-determination were important to them. Of this group, 36% had unmet needs around self-advocacy and self-determination. These percentages stayed consistent as participants were asked about their perspective on this topic over the next five years. There were significant differences in responses based on respondent race/ethnicity. Those who did not identify as a minority (white, non-Hispanic/Latinx) were more likely to think that self-advocacy and self-determination were issues of importance in the coming five years (85% compared to 71%) but were 3% less likely to report that they would need additional information or resources ($p<.05$).

Access to peer and family supports through groups and mentorship was important to participants. The opportunity to connect with parents, siblings and other people with IDD was identified as important to 73% of Needs Assessment participants. Of that 73%, 42% had unmet needs, with significantly more non-Hispanic/Latinx families having unmet needs than Hispanic/Latinx families. COVID-19 has also brought challenges to this type of interaction. As one professional described "We do a parent support group, but it's difficult to do it always remote. It's nice when parents are able to sit together and have coffee and talk about their challenges that week…and bounce ideas off of each other and be that support. Right now, we can only do it remote, but then we've got these technology barriers."

Among NCI IPS survey respondents in 2018-2019, 24% had attended or had the opportunity to attend a self-advocacy meeting, conference, or event. This is slightly lower than the average across NCI states (27%) and 5% lower than the 2017-2018 results.[cxviii] It means that only one in every four respondents was able to formally connect with other self-advocates in the past year.

Satisfaction with Services

The National Core Indicators represent a gauge on the services received by families, and their experience receiving those services. Table 29 provides a comparison of respondents from Missouri and other NCI states in several indicators.

Table 29. Perception of and Experience with Services Received, NCI		
2016-17 NCI Adult Consumer Survey Report		
Area Reported	**Missouri**	**Across NCI States**
Use self-direction or Fiscal Intermediary Services	39%	41%
Has a service plan	84%	86%
Took part in last service planning meeting, or had the opportunity but chose not to	98%	96%
Understood what was talking about at last service planning meeting	79%	81%
Last service planning meeting included people person wanted there	96%	92%
Person was able to choose services they get as part of service plan	77%	73%
Gets all the services listed in the service plan	86%	89%
2018-2019 NCI Child Family Survey Outcomes		
Area Reported	**Missouri**	**Across NCI States**

Always or usually satisfied with the services and supports their family receives	70%	75%
Someone in the family made the child's service plan	92%	83%
Child helped make the service plan	25%	18%
Have control and/or input over the hiring and management of the family's support workers	49%	50%
Service Plan includes all the services and supports the child needs	78%	83%
Service plan includes all the services and supports the family needs	73%	69%
Receive all the services listed in the service plan	82%	84%

The NCI also collects data on how many respondents receive different types of services through an IDD agency. Other services (82%) were the most common supports received by Missourians from an IDD agency, followed by in-home support (32%) and financial support (31%, Table 30). Missourians were 9% more likely to receive financial support from an IDD agency than those from other NCI states (31% compared to 22%). However, Missourians are less likely than the other NCI states to receive out-of-home respite services from an IDD agency (21% vs 31%, respectively).

Table 30. Services and Supports Received from IDD Agency, 2018

Services and Supports Received from State	MO	NCI States
Financial Support	31%	22%
In-Home Support	32%	39%
Out-of-Home Respite	21%	31%
Early Intervention	7%	12%
Transportation	19%	14%
Other	82%	54%

Child Welfare

In 2017, over 20,000 children received foster care-related services from Missouri Children's Division. There is little recent data on the percent of children in foster care with IDD, though the University of Missouri Center for Family Policy and Research estimates that between 44-66% of children in the foster care system experience emotional, behavioral, or mental health disorders. Unfortunately, less than a quarter (23%) of foster children have their mental health care needs met.[cxix]

The National Core Indicators collect data on abuse/neglect. Table 31 contains responses from the 2018-2019 Child Family Survey.[cxx] When comparing Missouri to other NCI states, there is a greater awareness of how to report abuse/neglect and grievances in Missouri. However, there were 2% more reports of child abuse or neglect in the past year in Missouri than across other NCI states, on average.

Table 31. NCI Items Pertaining to Child Abuse/Neglect

Item	Missouri	NCI States
Knows how to report abuse or neglect	83%	72%
Reported abuse or neglect if occurred within the past year	5%	3%
Appropriate people were responsive to a report of abuse or neglect within the past year	n/a	84%
Know the process for filing a complaint or grievance against provider agencies or staff	54%	48%
Satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved	n/a	55%

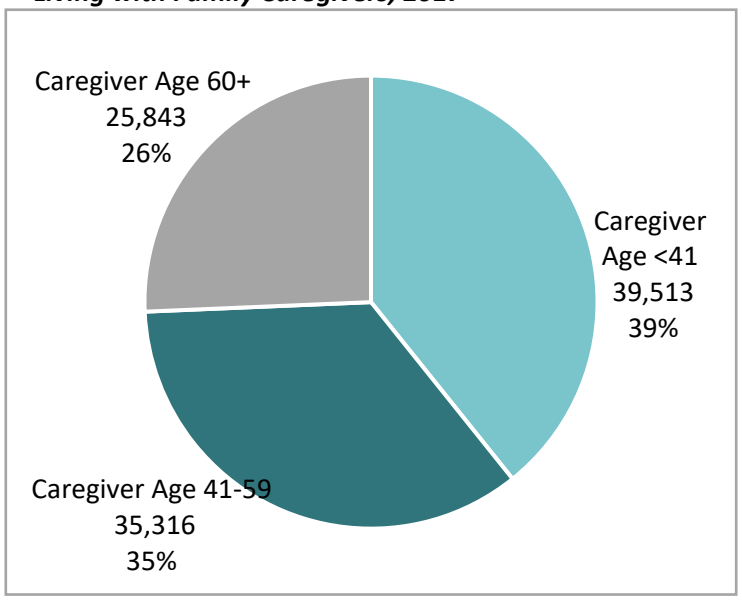
As previously mentioned, concerns about victimization and abuse surfaced in the listening sessions. Families and professionals expressed apprehension about mistreatment of their loved one by care providers and facility staff and discussed the importance of education and advocacy around preventing abuse. Several professionals mentioned that because of the pandemic and the transition to virtual education, there are increased concerns about unreported abuse.

Findings from the Needs Assessment survey showed that Parenting Skills Training was important to about 30% of respondents and that a third of those did not have their needs met in this area. The differences between responses from Hispanic/Latinx and non-Hispanic/Latinx participants were statistically significant. More than half of Hispanic/Latinx respondents thought Parenting Skills Training was important (just under 30% for non-Hispanic/Latinx respondents). Unmet need for both groups was just below 10%. Results were similar for anticipated future needs around Parenting Skills Training. Hispanic/Latinx respondents were more likely than non-Hispanic/Latinx respondents to indicate that Parenting Skills Training would be important in the future (40.0% compared to 18.3%) and that they will need additional information or resources on the topic (20.0% compared to 9.7%) ($p<.05$).

Aging

People with IDD are living longer than ever before and their caregivers are also aging. Based on the 2017 State of the States report, 26% of individuals with IDD lived with family caregivers over the age of 60 (Figure 19).[cxxi] Among all caregivers of people with IDD, 18.5% are over the age of 60, which is 1.5% higher than the national average. [cxxii]

Figure 19. Estimated Number of Individuals with IDD Living with Family Caregivers, 2017



Many agencies are adapting their services to accommodate the changing needs of those aging with IDD. The St. Louis-based Association on Aging with Developmental Disabilities, which was initially founded in 1989 focuses on this issue.

In the listening sessions and Needs Assessment survey, the topic of aging caregivers most often came up in discussions about future planning. Individuals with IDD, their families, and professionals all addressed the concerns that can arise when aging parents are no longer able provide care for their family member. One respondent wondered, “Who is going to help me when my mother isn’t here?” Just as future planning is needed to help people transition in or out of work, it is also needed to create a strategy to ensure that people with IDD are supported after their caregivers are no longer able to take care of them independently. Over half of the survey respondents indicated that they would need resources or information about future planning in the next five years.

Listening Session participants highlighted the need and importance of adequately planning for aging-related changes and many commented that they would like more strategies to engage in this process. Participants also noted that they were not aware of a particular entity that leads this type of planning effort, so planning often goes unaddressed in many families until a crisis occurs. People would like to see more agencies and organizations lead efforts around planning across the life course.

ANALYSIS OF STATE ISSUES AND CHALLENGES

CRITERIA FOR ELIGIBILITY FOR SERVICES

The following information outlines the current eligibility criteria for several programs.

Eligibility for MO HealthNet for People with Disabilities as of February 2021:[cxxiii]

- Is permanently and totally disabled. Disability, as defined and used by the Social Security Administration (SSA), is the individual's inability to be gainfully and substantially employed for one year or longer due to a physical or mental incapacity;
- Has net income less than the monthly threshold for an individual or a couple (see the Adult Standards Chart for current amounts). If monthly income exceeds this amount, the participant may become eligible when their incurred medical expenses reduce their monthly income below this limit. See Spend Down information on the Missouri Medicaid Audit & Compliance site;
- Who lives in Missouri and intends to remain;
- Who is a United States citizen or an eligible qualified non-citizen;
- If single, owns cash, securities or other total non-exempt resources with a value of less than the resource threshold for an individual or a couple (see the Adult Standards Chart for current amounts). (Note: Exempt resources include the home in which the participant or participant's spouse or dependents live, one automobile, household goods and certain other property. If a disabled child under age 18 is living with his parents, the non-exempt resources of the parents will be included); and,
- Is not a resident of a public institution except a public medical institution.

Eligibility for MO HealthNet for Kids as of February 2021:

- Who is under 19 years of age;
- Who applies for a social security number;
- Who lives in Missouri;
- Who is a United States citizen or an eligible qualified non-citizen (NOTE: receipt of MO HealthNet benefits does NOT subject qualified non-citizens to public charge consideration, see a full **list of benefits not subject to public charge** consideration);
- The parent must cooperate with Child Support Enforcement (CSE) in the pursuit of medical support; and
- Whose countable family income meets the income guidelines below

MO HealthNet for Kids Non-SCHIP (State Children's Health Insurance Plan)

Children (regardless of insurance status) are eligible if monthly family Modified Adjusted Gross Income (MAGI) does not exceed the following:

- 196% FPL for children under age 1
- 148% FPL for ages 1-18

MO HealthNet for Kids (SCHIP) [cxxiv]

Children with monthly family MAGI above the limits referenced above may be eligible under the State Children's Health Insurance Program if the following criteria are met:

- Uninsured children whose family MAGI is over the above limits but under 150% FPL, may be eligible for non-premium coverage.
- Uninsured children whose family MAGI is over 150% FPL up to 300% FPL may be eligible for premium coverage;
- Children in families with gross income over 150% FPL cannot have access to affordable health insurance and the family must pay a monthly premium. Premium amounts change July of each year. The premium is based on family size and income to ensure that no family pays more than 5% of their income for coverage. Refer to the Family Healthcare Program Descriptions below for further information.

Eligibility requirements for waivers available through Division of Senior and Disability Services[cxxv]:

Independent Living Waiver

- Age 18 to 64 years
- Have cognitive and/or physical disabilities
- Require meet nursing home level of care
- Have ability to self-direct
- Medicaid eligible for HCBS

Adult Day Care Waiver

- Adult 18-63 years
- Have impairments and unmet needs
- Requires nursing home level of care
- Medicaid eligible for HCBS

Aged and Disabled Waiver

- Age 65 years & older
- Age 63 or older—disabled
- Have impairment and unmet needs
- Requires nursing home level of care
- Has documented unmet needs
- Higher income level and spousal impoverishment
- Medicaid eligible for HCBS

AIDS Waiver

- Age 21 years and older
- Diagnosed with AIDS or HIV-related illnesses
- Requires specialized nursing home level of care
- Medicaid eligible for HCBS

Medically Fragile Adult Waiver

- Age 21 and older (aging out of HCY program at age 21)
- Previously required PDN through HCY
- Have a physical disability
- Requires ICF/ID level of care

Brain Injury Waiver

- Age 21 to 65
- Traumatic Brain Injury
- Require nursing home level of care
- Medicaid eligible for HCBS

Eligibility requirements for waivers available through the Department of Mental Health Waivers:[cxxvi]

DD Comprehensive Waiver

- Individuals With Intellectual and/or Developmental Disability
- Require ICF/IDD Level of Care

DD Community Support Waiver

- Individuals With Intellectual and/or Developmental Disability
- Require ICF/IDD Level of Care
- Has a place to live in the community
- Informal supports available
- Annual limit of $28,000 on waiver costs per person

MO Children with Developmental Disabilities

- Under the age of 18
- Have Developmental Disabilities
- Require ICF/IDD Level of Care
- Only Child's Income Considered; Allows Higher Income Level

Partnership for Hope

- Individuals With Intellectual and/or Developmental Disability
- Require ICF/IDD Level of Care
- Annual limit of $12,362 on waiver costs per person
- Waiver only operated in 114 Missouri counties plus St. Louis City

Eligibility requirements for Targeted Case Management:

All Medicaid eligible persons with a developmental disability as defined in 9 CSR 45- 2.010. A developmental disability is a disability which is attributable to:

- Intellectual Disability, cerebral palsy, epilepsy, head injury or Autism, or a learning disability related to a brain dysfunction; or

- Any other mental or physical impairment or combination of mental or physical impairments; and
- Is manifested before the person attains age twenty-two; and
- Is likely to continue indefinitely, and
- Results in substantial limitations as defined in 9 CSR 45-2.010(2)(F)(4) in major life activities, and
- Reflects a person's need for a combination and sequence of special, interdisciplinary, or generic care, habilitation or other services which may be of lifelong or extended duration and are individually planned and coordinated.

The target group of persons served through Division of DD TCM services does not include individuals who are served in Institutions for Mental Disease (IMD) who are between the ages of 22 and 64, nor to individuals who are inmates of public institutions.

To be eligible for TCM services provided by support coordinators of the Division of DD, of a Regional Office, an approved County Board or other not-for-profit agencies, an individual must be determined to:

- Have a developmental disability as defined in 630.005 RSMo (and 9 CSR 45- 2.010) and determined by a Division of DD Regional Office;
- Be eligible for MO HealthNet in order for the TCM Provider to submit claims to MO HealthNet for reimbursement;
- Not reside in ICF/ID or other MO HealthNet-funded nursing facilities unless the person has a transition plan to move into the community.

The Missouri Department of Social Services, Family Support Division (FSD) is responsible for determining if individuals are eligible for MO HealthNet. Only MO HealthNet eligible individuals who are enrolled for services through the Division of DD are eligible for TCM that is billable to MO HealthNet. The individual must be enrolled with a Regional Office with an eligible program code on the day of service, in order to be eligible for the TCM program.

If the individual is eligible for Division of DD services and MO HealthNet, a support coordinator will explain that all support coordination time spent on behalf of the person will be logged and billed to MO HealthNet, including time spent in meetings or on phone calls, making contacts, and completing documentation. Communication must assure the person or their family or guardian that billing MO HealthNet for TCM in no way limits the person's eligibility for other MO HealthNet services or the amount of those MO HealthNet services he or she may receive.[cxxvii]

Eligibility requirements to receive a loan through Missouri Assistive Tech:

- Be a Missouri resident
- Be a person with a disability, a person with an age-related change, or a family member applying on behalf of a family member with a disability or age-related change. Applicants must be legally old enough to enter into a contract
- Loans can only be used for qualifying items (i.e. AT or assistive technology, durable medical equipment or DME, vehicle access modifications, homeowner access modifications, hearing aids, etc.)
- Have obtained a quote from a vendor for the items to be purchased with the loan. You chose where the item or service is purchased from
- Be able to afford a monthly loan payment

Additional information on AT can be found in "Availability of Assistive Tech."

Challenges to Accessing Services

Some Needs Assessment survey respondents expressed frustration at the complex nature of the IDD service system in the state, specifically the complicated eligibility guidelines and network of services and waivers. It is difficult for families to determine where to start and even harder to understand the intricacies of services, eligibility, and more. Many families rely on these services, but they are rarely confident in navigating the system. Also, some families are concerned about losing services if they attempt to get a job or earn more income. "Families like mine are being held in a constant state of poverty under threat of losing services," one respondent wrote.

> ***"What a maze of services there is. I'm educated and have worked in mental health for decades—it's still confusing and difficult…There are so many things out there and there's no one-stop shop options for finding services for kids with disabilities."***
>
> ***-Parent and Professional***

A complicated and confusing service system impacts the ability of people with IDD to live the lives they want to live. Survey participants were asked to identify the biggest barriers they experience around having a high quality of life and doing the things they want and need to do. The most commonly named obstacles were related to a lack of knowledge of what is available or how to tap into resources. Respondents were often unsure about how to explore service options—they were unaware of what services were available to them, who to go for more information, or in some cases, what they need to solve their problem. When asked about the challenges to getting supports and services that families need, 41% said that not knowing what is available was a barrier. Another 25% didn't know who to ask about resources and 25% said that they weren't sure what services they needed. Other questions related to the barriers in living situations, life transitions, and employment had similar results. This confusion is a direct result of a complicated services system with multiple, disconnected entry points and few sources of comprehensive information.

BARRIERS TO FULL PARTICIPATION OF UNSERVED AND UNDERSERVED GROUPS OF INDIVIDUALS WITH IDD AND THEIR FAMILIES

Barriers faced by people with IDD were explored through the collection and analysis of primary and secondary data. After a review of data from sources such as the U.S. Census, State of the States, NCI, and agency reports, rural and Hispanic/Latinx populations were identified as being underserved groups in Missouri. Primary data collected by the UMKC-IHD team further supported this finding and provided context for the unique barriers to full participation experienced by these communities.

Primary data collection consisted of a Needs Assessment survey and Listening Sessions/interviews with over 80 Missourians. The Needs Assessment survey was distributed to individuals with IDD, their families, professionals in the field, and other stakeholders. Questions spanned four domains (what you do, where you live, what families need, and future needs) and respondents were asked about the importance of a variety of items in their lives and if they had unmet needs related to these items. Bivariate analyses were conducted to explore results by race/ethnicity. Findings indicate that there were significant differences between Hispanic/Latinx and non-Hispanic/Latinx participants on 11 unmet need-related items, and in 10 of those areas, Hispanic/Latinx respondents had higher levels of unmet need.

Semi-structured Listening Sessions were also conducted in which attendees were asked about challenges, successes, and opportunities in the four question domains outlined above. Qualitative

findings highlight the significant access and support challenges experienced Hispanic/Latinx Missourians and rural communities. Hispanic/Latinx families discussed challenges associated with navigating language, cultural, and systemic barriers. Qualitative findings also illuminate the barriers Missouri's rural communities experience due to geographic location and rurality. More detailed information on the obstacles that hinder full participation from these groups—and their ideas for improving the lives of people with IDD in Missouri—are outlined below and expounded upon in the full report, *MODDC Data Collection Grant: Results From the 2020 Community Needs Assessment and Listening Sessions*. Additional information on themes and direct quotes from participants are also included in this report.

As mentioned, individuals living in rural areas face unique challenges in accessing IDD services and engaging fully in their communities. According to respondents, the lack of services in many rural counties and the economic and logistical challenges of travelling to more urban areas to receive services is an impediment to many families. Participants described how rural communities often have few or no local service providers. This also extends to finding DSPs to provide in-home care. One professional noted, "I think the obvious challenge with the rural versus suburban or urban is resources—the access that they don't have." Parents described driving hours to other cities or even other states for services for their children.

Knowledge of and access to technology, was another challenge experienced by many participants in rural areas. Access to technology and an understanding of how to use the tech is only one barrier. In some cases, even when people have the devices and knowledge to use it, they lack reliable broadband internet access. This hinders participation in telehealth appointments, virtual case management meetings, social calls, and more. This has been particularly challenging during COVID-19.

Another difficulty that disproportionately impacts rural areas relates to how people with disabilities are integrated into the community. Participants reported that community education and self-advocacy education is sparse in rural areas and this can impinge upon individual rights and experiences. One parent /professional described the mentality as "we've got to take care of this person and make them breakfast. We're not going to teach them how to make breakfast, we're just going to make it." This environment makes it difficult for people with IDD and their families to practice self-determination and self-advocacy. Overall, participants highlighted the significant need for more community education, particularly for schools, employers, landlords, and community organizations.

A lack of other resources and services also impacts the quality of life of people with IDD in rural Missouri. Limited access to public transportation makes it difficult for people to do the things they need and want to do. It constrains their options for housing, employment, and socialization and makes community engagement difficult. Few options for peer-to-peer support or social groups make it difficult for people with IDD and their families to connect with others. Limited information and resources on services or educational opportunities also presented a challenge for families looking for other ideas or options. In several cases, the issues and challenges expressed by participants living in rural Missouri looked different from those living in urban or suburban environments.

As noted, Hispanic/Latinx participants also challenges associated with accessing services and fully participating in their community. The Needs Assessment survey and a Listening Session were conducted in Spanish and an individual interview was completed with a professional working with Hispanic/Latinx families to better understand the perspectives of this population. Cultural competence was continuously identified as a key component of effective engagement with Hispanic/Latinx families. While ensuring

that resources and materials are available in Spanish was identified as an important need, participants clarified that in some cases, simply translating materials is not enough to effectively connect with a Hispanic/Latinx audience. Adapting the style, content, and means of communication is also necessary to effectively disseminate information.

Technology is another barrier impacting families' ability to engage and stay active. Some participants shared that they are not confident using Zoom, doing telehealth appointments, and using other technologies. Others identified cost of broadband internet services as barrier.

Cultural competence of service providers was also identified as an issue in Missouri. Participants reported difficulty finding service providers, specifically mentioning roles like service coordinators and health care providers, who are bilingual and who understand culturally and linguistically diverse populations. One participant commented, "[finding] professionals speaking their language is always a trouble. Making sure that they have an interpreter or that they bring one of their kids to serve as an interpreter."

The complex IDD service system also presented challenges for Hispanic/Latinx participants. Navigating the complicated network of services was identified as a barrier for many families. The impact of parental immigration status on eligibility for services was an additional concern noted by some participants. One parent said, "I would like when Latino families ask for help for their children who are citizens…I would like you to take into consideration that…some of our parents do not have documentation…Their children have all the right, just like any other American child, to receive services, therapies and all that, but for fear that they are not in this country legally, they do not fill out applications." Additionally, families feel that even when they are connected to formal services to receive support through schools, they often fall through the cracks.

Employment opportunities (particularly summer employment) were also areas where Hispanic/Latinx participants identified gaps. A dearth of available work opportunities is a barrier to community engagement for this population. Similarly, participants identified a need for more community education of employers and community members so that people with IDD feel safe and welcome and in their communities. Other participants noted that concerns about discrimination related to ethnicity and native language prevent them from fully engaging in their community.

Hispanic/Latinx participants suggested that expanding technology and internet access could improve their lives. Specific needs identified by participants included assistance with paying for internet services and education on how to use software like Zoom, help navigating telehealth appointments, or ensuring that interpretation services are regularly available. Participants also provided suggestions for how information can most effectively be shared in the Hispanic/Latinx community. Information needs to be translated and adapted to be culturally and linguistically appropriate for Missouri's Hispanic/Latinx population. One parent said, "We especially need material in our language—material in our language based on our culture, understanding in that part, in the cultural part because we are a little different from Americans." A final suggestion was for support groups and social work support for Hispanic/Latinx families. These groups could be sources of social support as well as educational opportunities and information.

Over the past several years, MODDC has been working to expand the cultural and linguistic diversity of its membership and programs, with a focus on the Latinx community. MODDC has worked to build and

nurture relationships with the Latinx community through targeted outreach, relationship building, and working with cultural brokers. The organization's trainings, website and much of its materials are available in Spanish (as well as other languages). In addition, MODDC leadership has been working with the Governor's staff to advocate for a diverse group of appointees. As part of its work, MODDC has connected over 50 Latinx families to needed supports and services (surpassing the goal of 30). Other initiatives, such as Project Alianzas and Latino Leadership and Advocacy Project also focus on building relationships and effectively connecting with Missouri's Latinx populations. Both initiatives provide an opportunity to hear from the Latinx community, provide support and information, and connect families to needed services.

Despite the efforts and progress that have been made, challenges in accessing needed services and information remain for the Hispanic/Latinx community. Hispanic/Latinx participants specifically highlighted the need for more culturally sensitive services and more resources in Spanish. A professional who works with Latinx families noted that while there have been increased efforts to provide culturally competent services, this work is not as comprehensive or consistent as it needs to be to adequately serve Missouri's Hispanic/Latinx population.

AVAILABILITY OF ASSISTIVE TECHNOLOGY

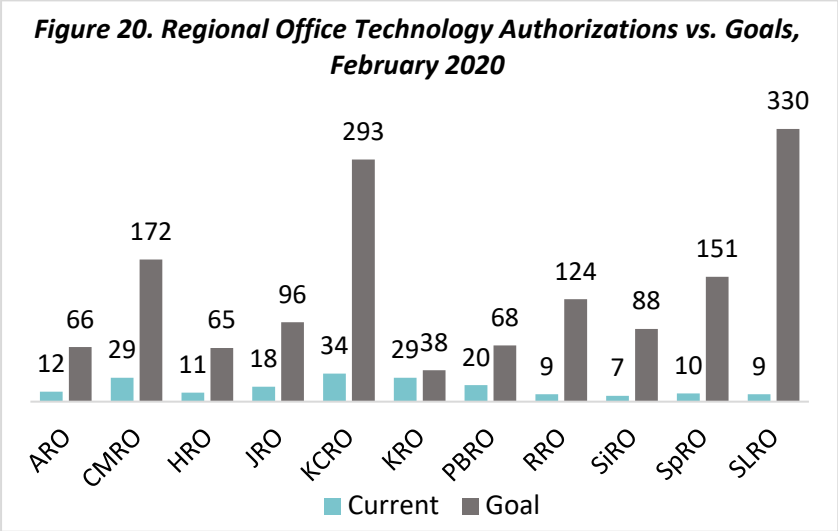
Missouri Assistive Technology (MoAT) works to increase the access to assistive technology (AT) for Missourians with disabilities. The organization works to achieve this mission by loaning AT devices, providing trainings to help people use technology, and distributing low-interest loans. Examples of AT include a voice assistant device which helps with medication reminders, accessible vehicles and power chairs, and adapted eating utensils.[cxxviii]

Each year, MoAT provides services to thousands of Missourians with disabilities and the website includes numerous personal testimonies from AT users over the years. During FY 2019, MoAT delivered 7,640 assistive devices to the community and provided support services to 23,671 Missourians with disabilities, family members and professionals. In 2019, MoAT conducted nearly 1,000 trainings and public awareness events, re-utilized over 3,000 devices, and loaned nearly 2,000 out (Table 32).

Table 32. Services Provided by Missouri Assistive Technology, 2019

Count	Topic
1,931	Assistive devices loaned
2,006	Device demonstrations conducted
2,020	TAP for Telephone & Internet devices provided
28	Families assisted through the Kids Assistive Technology Program
32	Show Me Loans approved
228	Deaf-Blind devices provided
62	MFP (Money Follows the Person) consumers assisted
265	Students with disabilities benefitted through ATR
3,074	Gently used devices transferred to new owners
9,915	Individual information and assistance requests handled
7,400	Individuals attended trainings, workshops and outreach events

The DDD is also committed to empowering individuals through assistive technology through their Technology First Initiative. Technology First "is the practice of considering the use of technology before direct support professionals" and may include medication reminder devices, phone apps, door or window sensors, communication devices and more.[cxxix] According to the Technology First Dashboard, 52 of Missouri's 114 counties were accessing AT and/or Remote Supports in February 2020 and 52% of TCM providers were supporting individuals with AT. In 2019 (the program's first year) it reached over 1,000 people through outreach events.



As of February 2020, however, all Regional Offices were below their goals for Technology Authorizations, indicating that there is room for growth in this area (Figure 20).[cxxx]

WAITING LISTS

The Missouri Code of State Regulations defines a waiting list as, "a list of all people who have requested but are not currently receiving series from the division." Missouri's wait lists are subdivided into seven categories based on age, eligibility for MO HealthNet, and needs. The Prioritization of Need (PON) score is used to determine access to services when funding is limited and wait lists are needed. PON scoring is a tool that aims to provide a global picture of a person's needs, identify unmet support needs that place a person at risk, and document why there are unmet needs. It assigns a score (1-12) to an individual based on their level of need and this score is used to determine their priority. PON scoring is applicable to the following programs: comprehensive waiver, community support waiver, Lopez waiver, autism waiver, or community services funded with general revenue appropriations and purchased through DMH POS system. Those who are on a wait list for state general revenue funded services are prioritized based on PON. If multiple individuals have the same PON score, the individual who has been on the wait list for the longest time is prioritized.

The wait lists for the HCBS Partnership for Hope waiver is managed a bit differently. When funding is limited, the individuals who are in crisis will be served first, with priority given to the individual who has been waiting the longest, if multiple people are in crisis.[cxxxi]

The Division of Developmental Disabilities released the following information on the waitlist for in-home care for Medicaid eligible individuals on February 1, 2021. The UR score (1-12) is the Utilization Review score, which includes the PON score. These numbers indicate that there are 587 people on the waitlist for in-home care across the state of Missouri (Table 33).[cxxxii] In December 2020, there were 718 people on the waitlist, meaning that the waitlist decreased by 131 people during that two month timeframe. There are 10 people per 100,000 waiting on in-home services.

Table 33. In Home Wait List for Medicaid Eligible Individuals by UR Score

	1	2	3	4	5	6	7	8	9	10	11	12	Total
Albany	1	1	3	0	0	0	1	2	1	0	0	0	9
Central MO	6	2	5	3	2	1	3	0	3	6	7	9	47
Hannibal	1	0	2	0	0	0	0	0	0	0	0	0	3
Joplin	0	1	0	4	0	3	1	1	0	5	4	4	23
Kansas City	20	19	50	14	5	1	1	2	3	3	20	8	146
Kirksville	0	1	3	0	0	0	0	1	1	0	0	0	6
Poplar Bluff	1	4	3	2	2	1	5	1	0	2	0	0	21

Rolla	0	0	2	1	0	1	2	1	4	9	2	0	22
Sikeston	7	17	15	5	3	0	4	2	2	6	3	3	67
Springfield	1	4	7	3	3	7	6	5	7	4	32	16	95
St. Louis	7	29	58	11	4	2	2	1	2	4	11	17	148
Total	44	78	148	43	19	16	25	16	23	39	79	57	587

Table 34 shows the number on people who are Medicaid eligible and who are on a waitlist for residential services by region in February 2021. As of February 1, 2021, 180 people are on the wait list, four fewer than in December 2020.[cxxxiii] There are 3 people per 100,000 waiting on residential services.

Table 34. Residential Wait List for Medicaid Eligible Individuals by UR Score										
	1	**2**	**3**	**4**	**6**	**9**	**10**	**11**	**12**	**Total**
Albany	0	0	0	0	0	0	0	0	6	6
Central MO	1	1	2	1	0	0	0	0	30	35
Hannibal	0	0	0	0	0	0	0	0	2	2
Joplin	0	0	0	0	0	1	1	0	12	14
Kansas City	0	0	0	0	0	0	0	0	37	37
Poplar Bluff	1	0	0	0	0	0	0	0	3	4
Rolla	0	0	0	0	0	0	0	0	13	13
Sikeston	0	0	0	0	0	0	0	0	9	9
Springfield	0	0	0	0	1	0	0	0	8	9
St. Louis	0	1	3	1	0	0	1	1	44	51
Total	2	2	5	1	1	1	2	2	164	180

Although these waitlist numbers are low compared to other states, respondents of both the Needs Assessment survey and the listening session noted that waitlists were a significant concern to them and their families. They discussed how waiting months or even years for services was not uncommon, and that time spent on waitlists has been increasing. Waitlists were a source of stress for families trying to plan for the future, as they are uncertain of when services will be available to them.

Participants expressed frustration, confusion, and disappointment surrounding the length of waitlists for services in Missouri. One professional commented, “A number of families have a sense of hopelessness that that they can't get the funding that they need to get the services they need. They're now looking at sitting on waiting lists for an indefinite period of time. You know, you used to be able to go through the processes and based on how critical the need was, it would be prioritized…and that's no longer the case.”

ENTITY WHO MAINTAINS THE WAIT-LIST DATA IN THE STATE

The Missouri Department of Mental Health manages the waiting list information for in home and residential services.

ADEQUACY AND RESOURCES

Missouri Department of Mental Health released its FY 2022 Budget Request in October 2020. Budget requests from the three-year period between 2020-2022 indicate that the Division of Developmental Disabilities requested less funding for their programs and services in 2022 than in 2021 or 2020.[cxxxiv] Table 35 contains information from budget requests made for the DDD between 2020-2022. Funding for

Habilitation Center Room and Board Funds has remained consistent during this period and funding for the Developmental Disabilities Trust Fund decreased from $10,000 in 2020 to zero in 2021 and 2022. DDD's budget is largely funded by federal funds ($965,671,194 per the 2020 budget request) and general state revenue ($521,061,402 in 2020).[cxxxv]

Table 35. Division of Developmental Disabilities Department Budget Request, 2020-2022				
Fund Name	**Fund**	**Amount 2020**	**Amount 2021**	**Amount 2022**
General Revenue	0101	$521,061,402	$504,564,978	$477,559,655
Federal	0148	$965,671,194	$943,039,799	$874,314,574
Mental Health Interagency Payment Fund	0109	$10,130,157	$10,130,157	$10,130,157
Intergovernmental Transfer Fund	0147	$0	$0	$0
Mental Health Housing Trust Fund	0277	$0	$0	$0
Compulsive Gambler's Fund	0249	$0	$0	$0
Health Initiatives Fund	0275	$0	$0	$0
Mental Health Earnings Fund	0288	$0	$0	$0
Inmate Revolving Fund	0540	$0	$0	$0
Health Families Trust Fund	0625	$0	$0	$0
Debt Offset Escrow	0753	$0	$0	$0
ICF for Individuals with IDD Fund	0901	$0	$0	$0
Revolving Administrative Trust Fund	0505	$0	$0	$0
Abandoned Transfer Fund	0863	$0	$0	$0
Habilitation Center Room and Board Fund	0435	$3,416,027	$3,416,233	$3,416,027
Mental Health Trust Fund	0926	$0	$0	$0
Mental Health Local Tax Match Fund	0930	$11,728,609	$9,904,538	$9,904,538
Developmental Disabilities Waiting List Trust Fund	0986	$10,000	$0	$0
DMH Federal Stimulus Fund	2345	NA	NA	$0
Total		**$1,512,017,389**	**$1,471,055,705**	**$1,375,325,054**

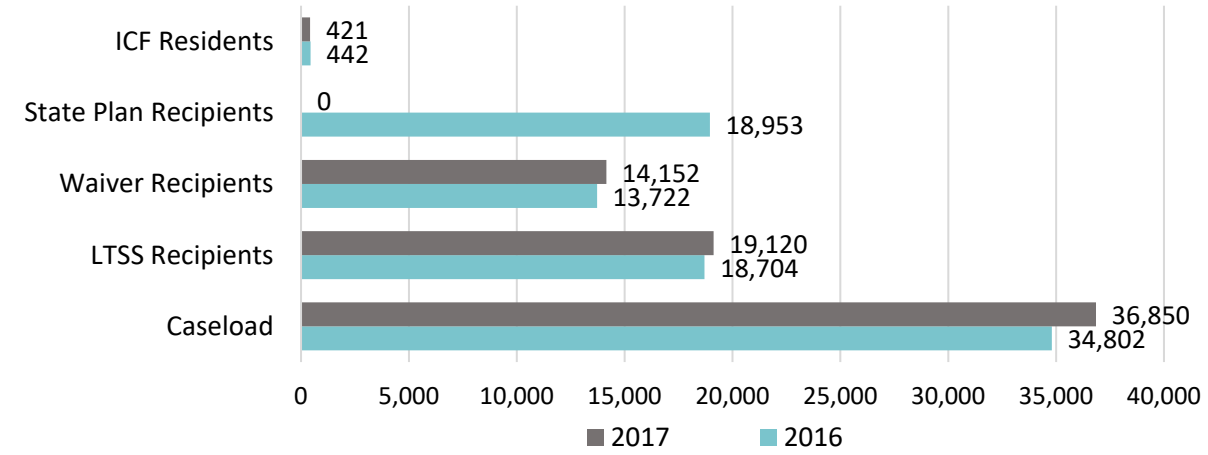
The 2022 budget request also explores the actual and projected cost of In Home, Self-Directed, and Residential services for Missouri's DD population. Data indicates that the cost of serving individuals in their home is significantly lower than serving individuals in a residential setting. In 2020, the average annual cost of In Home services was $13,741 per person while it was $122,071 per person for those living in residential settings. A similar difference is projected for 2021, 2022, and 2023 (Table 36). Clearly, the provision of In Home and Self-Directed services is more cost effective than residential placement, so Missouri's trend towards HCBS will likely continue. The percent of waiver participants who are participating in self-directed services has been growing over the past several years, from 12.3% in 2018 to 14.9% in 2020.

Table 36. Average Annual Cost Per Consumer			
	In Home Services	**Self-Directed Services**	**Residential Services**
2018	$12,720	$20,630	$103,965
2019	$13,656	$21,721	$109,939

2020	$13,741	$25,716	$122,071
2021 (Projected)	$13,878	$26,230	$123,292
2022 (Projected)	$14,017	$26,755	$124,525
2023 (Projected)	$14,157	$27,290	$125,770

Services Provided

Figure 21. People Served by IDD Agencies, 2016 & 2017



Missouri's Department of Mental Health provided services to 36,850 Missourians with disabilities in 2017, approximately 2,000 more than were served in 2016. This accounts for 20% of the population of patients served by DMH and 53% of their total mental health spending (Figure 21).[cxxxvi] The Division of Developmental Disabilities provides habilitation and rehabilitation services, case management, care coordination, residential and employment supports and other supports and services. It operates out of five regional offices, six satellite offices, four habilitation centers, and three community supported agencies. Most services are delivered through a network of 800 program providers in the community. These services include in-home supports, residential services, support coordination, and autism services.

According to the State of the States, in 2017, the Missouri DDD served approximately 15,020 families with disabilities. The number of families served by the DDD has been steadily growing over the past several decades. Most families (8,870) receive services through supported living and PA. Approximately 5,860 receive family supports and 290 receive supported employment services. These three services make up nearly half (46%) of IDD expenditures in Missouri.[cxxxvii]

Table 37 shows the most recent available data on the number of individuals served by waivers. The table includes information on the number of individuals receiving waivers and the cost of the waiver for nine DHSS and DMH waivers. There is no data for the Brain Injury Waiver, as it was a new waiver in 2020.

Table 37. Number of People Served by Waivers in 2017 and 2018

Waiver	People Served 2017	Cost of Waiver 2017	People Served 2018	Cost of Waiver 2018
DHSS Waivers[cxxxviii]				
Aged and Disabled	15,829	$63,871,439	16,378	$63,051,542

Independent Living	270	$1,888,306	413	$3,655,083
AIDS	91	$2,380,590	78	$2,402,565
Medically Fragile Adult	167	$17,852,917	169	$17,100,956
Adult Day Care	1,711	$16,239,445	1,731	$16,957,354
DMH Waivers[cxxxix]				
DD Comprehensive	8,614	$800,126,690	8,629	$823,618,899
DD Community Support	2,946	$62,069,232	3,637	$80,809,628
MO Children with DD	313	$2,943,180	311	$2,881,259
Partnership for Hope	2,657	$13,158,325	2,184	$8,416,976

Additional data from DMH's 2022 budget request has similar estimates for the number of individuals served by waiver (shown in Table 38). Projected participation in waiver programs between 2021-2023 is expected to mirror rates in 2020.

Table 38. Number of Consumers Served by DMH DD Waivers, 2018-2020

	FY2018	FY2019	FY2020
Comprehensive Waiver	8,619	8,691	8,532
Community Support Waiver	3,620	4,262	4,155
MO Children with DD Waiver	319	339	332
Partnership for Hope Waiver	2,365	2,324	1,968
Total	**14,932**	**15,616**	**14,987**

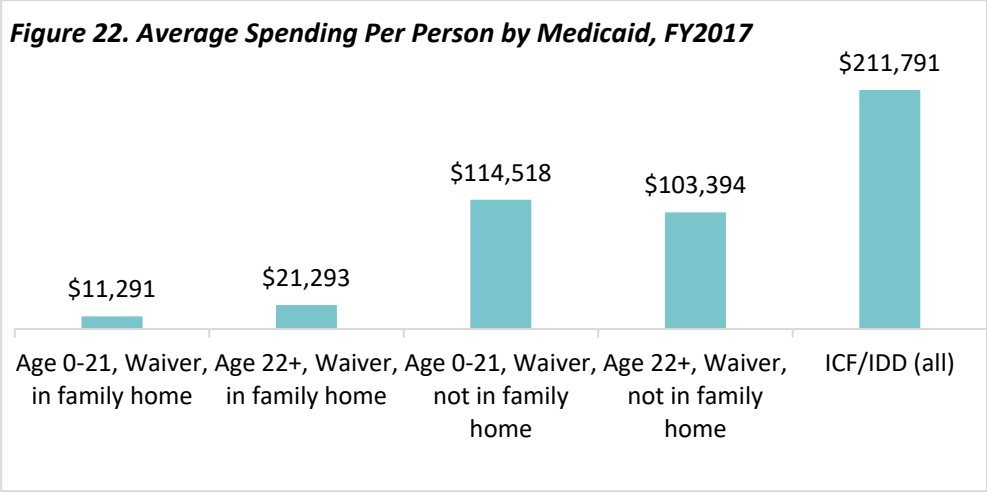
Of the types of In Home services provided through the Comprehensive Waiver, Community Support Waiver, MO Children with DD Waiver and Partnership for Hope Waiver, Personal Assistant services (37%), Self-Directed Services (24%) and Day Services (21%) were the most commonly used. Community Integration, Transportation, Professional Services, Respite, Employment, and Specialized Equipment are other examples of services that were used 5% or less of the time.[cxl]

As mentioned, there are 22 CILs across the state of Missouri that provider services to people with disabilities to foster independence and community participation. In FY2018, 15,825 individuals were served by CILs and 15,440 were served in 2019. In 2021, these CILs are projected to serve approximately 24,000 Missourians. Missouri's 2021 and 2022 budget for CILs was $5,153,103, slightly higher than the amount spent in 2020 ($4,813,419). [cxli]

Employment services are requesting increased funding. Sheltered workshops accounted for $23,195,245 of the state budget in FY 2020. In 2021, $26,041,961 was budgeted to support sheltered workshops for people with disabilities. In 2020, the budget for vocational rehab was $54,008,308 and in 2021 the budget was increased substantially to $68,893,464.[cxlii]

Medicaid Services

Medicaid spending per capita for people with IDD varies by age and residence. Individuals who have a waiver, are under 21 and living at home have the lowest spending per person while those in ICF/IID settings have the highest (Figure 22). [cxliii]



In 2017, it was estimated that there were 14,576 people receiving Medicaid waiver and ICF/IID services. There were 247 people on the waitlist for Medicaid waiver LTSS, with 231 receiving Targeted Case Management services and 124 waiting to move from their family home. These data indicate that there needs to be a 2% increase in services in Missouri to serve all those who are on the waitlist. [cxliv] Based on Missouri's population of 6.14 million, this means 9.8 per 100,000 people are waiting for LTSS.

In recent years, DDD has been transitioning its service delivery model from one that responds to crises to one that focuses on prevention. A large part of this has been providing care in the least-restrictive setting possible, which has resulted in the influx of HCBS services and waivers. For those who receive a waiver, it is possible to receive services in their home, which is both cost effective and preferable for many families. In FY 2018, the projected annual cost of in-home supports was $11,769, while residential treatment was projected to cost $99,010 a year.[cxlv]

Future Needs

To access adequacy of resources, UMKC-IHD developed a Needs Assessment survey that asked respondents about their anticipated needs related to activities/work, living arrangements and family needs in the next five years. Respondents were asked to report how important the issue is to them, and if they think they will need additional information or resources in the future. With this approach, data was captured about which items are priorities to people and the potential for future unmet need. The Needs Assessment survey was developed by UMKC-IHD with the assistance and insight of the Living Well team and MODDC staff. It was distributed throughout the state to individuals with IDD, families, caregivers, professionals, and other stakeholders. Additional information on the survey and its distribution can be found in the Introduction.

In general, the anticipated future need for information and resources was high; in 18 of the 45 categories, over a third of respondents indicated that they would require additional support in the future. Future planning was the area with the highest need. More than half of all respondents (50.8%) indicated that they would need more information or supports related to long-term planning in the next five years. Many of the categories that had a high anticipated need for information or resources in the future were also the areas where respondents identified that they had current unmet needs.

Social, leisure and recreation activities had high anticipated needs, as did community integration opportunities and access to paid services. Almost 47% of respondents indicated that they will need additional resources and information about paid services in the next five years. Given the reduction in the DDD's budget in coming years and concerns about waitlists, it is alarming that many respondents

plan to rely on these, to some degree, in the future. The projected need that individuals and families have for paid services does not align with the current state of paid services in Missouri or the reduction in DDD budget requests over the past several years.

More than a third of respondents also indicated that they would need resources related to disability specific activities, independent living skills, and self-determination, indicating interest in self-advocacy and independence in the next few years. Supports for families, including in-home and out-of-home respite and relationships with other families were also seen as areas that were important and are associated with high need.

When asked about future needs, it was more likely for Hispanic/Latinx respondents to report anticipated future needs than non-Hispanic/Latinx respondents. This was the case for 33 of the 45 items in the Future Needs section. Behavioral Supports was the item with the biggest difference in needs between ethnicities; 52.0% of Hispanic/Latinx participants reported unmet needs in this area while 24.4% of non-Hispanic/Latinx respondents did ($p<.05$). Responses related to Personal Care Assistance, Summer Employment, Planning for the Transition from School to Work/Adult Life, and Parenting Skills Training also had statistically significant differences between Hispanic/Latinx and non-Hispanic/Latinx respondents. Table 39 contains a full list of items with overall levels of unmet need and unmet need by Latinx ethnicity.

Table 39. Future Unmet Need by Latinx Ethnicity			
Topic	**Important: but I will need additional info or resources (%)**	**Latinx: Have Unmet Needs (%)**	**Non-Latinx: Have Unmet Needs (%)**
Having a long-term plan in place for care	50.8	50.0	51.0
Social activities in your community	48.8	53.8	48.3
Access to resources in my community	47.8	52.0	47.5
Access to paid services	46.8	52.0	46.9
Friendships or relationships with others in your community	45.4	63.0	44.6
Leisure / hobby activities	44.4	46.2	44.3
Working in the community	41.6	53.8	41.3
Disability specific activities (e.g. People First)	41.2	42.3	40.2
Achieving personal goals	40.5	44.4	39.6
Parks and recreation activities	39.7	36.0	39.8
Independent living skills training	37.8	50.0	37.4
Self-advocacy and self-determination	37.3	44.4	36.2
Fitness/wellness activities or programs	37.3	42.3	37.3
Living in an apartment or home with supports	36.2	50.0	35.8
Access to networking with other families	35.2	23.1	36.0
Occasional out-of-home support (respite)	35.1	44.0	35.5
Occasional in-home support (respite)	33.9	48.0	33.6
Support coordination / case management services	33.8	42.3	33.3
Volunteering in the community	32.4	32.0	33.0
Financial planning	31.7	38.5	32.1
Access to medical supports and services	31.1	42.3	30.3
Financial management (e.g. budgeting)	30.7	36.0	31.2
Personal care assistance	30.7	54.2	30.0
Pre-employment training	28.7	44.0	28.8
Planning for transition from school to work/adult life	28.1	50.0	27.5
Assistive technology	27.6	36.0	26.8
Adaptive equipment for health and safety	27.0	33.3	26.2
Membership in organizations or clubs	26.2	29.2	26.1
Behavioral supports	26.0	52.0	24.4
Working in summer employment	25.2	29.2	25.2
Living independently without supports	24.6	36.0	23.9
Family/individual short-term counseling	22.7	30.8	22.1
Living in a group home/supervised residential setting	19.7	16.0	20.0
Adult education (GED/continuing education/college)	19.4	28.0	19.4
Feeling safe in your community	17.8	26.9	16.7
Retirement supports	16.0	20.0	15.9
Before or after school care	15.7	32.0	15.1
Working in a sheltered workshop	15.1	7.7	16.0
Planning for transition from work to retirement	14.7	8.3	14.9
Feeling safe in your home	13.0	15.4	12.5

Having privacy in your home	11.9	11.5	11.5
Living with parents/family	10.9	3.8	10.6
Parenting skills training	10.3	20.0	9.7
Planning for transition into early childhood education (k-12)	10.2	8.3	10.2
Living in institutional care or nursing facility	7.9	8.3	7.9

In addition to investigating differences in responses by Latinx ethnicity, bivariate analyses were conducted to explore any differences by minority status. Analyses revealed that eight Future Needs items had statistically significant differences between White, non-Hispanic/Latinx populations and minority populations: Before and After School Care, Fitness/Wellness Activities and Programs, Access to Medical Supports and Services, Living in a Group Home/Supported Residential Setting, Retirement Supports, Planning for Transition to K-12, Self-Advocacy and Self Determination, and Leisure/Hobby Activities. In general, white, non-Hispanic/Latinx respondents anticipated needing more resources related to recreation activities, community engagement and independent living skills, while minority respondents anticipated more unmet needs for access to services, medical supports and resources.

Adequacy of Information and Resource Connectivity

Respondents made a notable connection between the adequacy of resources and effective information dissemination. Participants commented that while there are often existing resources or supports available to families, information about these services is not always made readily available, or details about the resources are not widely understood. These observations about the challenges of information dissemination closely resembled the Needs Assessment survey's findings, which showed that a lack of knowledge/lack of awareness of resources presented barriers to families (discussed in "Challenges to Accessing Services").

In response, participants identified a need to make digestible, applicable, and culturally tailored information about resources more available. Families and professionals both explained that they often experience a sense of overwhelm when presented with a long list of resources: "There's all these great resources, but I'm just overwhelmed at where to start.'" When families seek resources, they usually need specific information relevant to their situation or life stage. Families said that when they receive a comprehensive list of referrals, it is hard to know where or how to start. Another important consideration in information dissemination is adapting resource to be culturally sensitive. This includes translating materials into multiple languages as well as adapting content to reflect different audiences and a variety of cultures.

Rehabilitation Centers and ICF/IID Facilities

The state of Missouri currently operates ICF/IID facilities and four habilitation centers throughout the state. The Missouri Department of Health and Senior Services reviews and monitors these facilities and reports Statements of Deficiencies and Plans of Corrections. Plans of Corrections are required to address the deficiencies outlines in the Statement of Deficiencies. Summaries of the reported deficiencies from several centers from 2019-2020 can be found below.

Bellefontaine Rehabilitation Center Statement of Deficiencies, 3/12/2019	
Deficiency Area	Expectation Not Met
Protection of Clients Rights	The facility must ensure privacy during treatment and care of personal needs
Management of Inappropriate Client Behavior	The use of systematic interventions to manage inappropriate client behavior must be incorporated into the client's individual program plan
Dining Areas and Service	The facility must assure that each client eats in a manner consistent with his or her developmental level

Sunnyhill, Inc. Statement of Deficiencies, 10/30/2019	
Deficiency Area	Expectation Not Met
Means of Egress Requirements	The facility must meet the applicable provisions of either the Health Care Occupancies Chapters or the Residential Board and Care Occupancies Chapters of the Life Safety Code National Fire Protection Association (NFPA)
Sprinkler System Installation	The facility failed to provide complete sprinkler coverage in all habitable areas of the Living Center as required by the NFPA
Sprinkler System Maintenance and Testing	The facility failed to maintain the sprinkler system in accordance with the National Fire Protection Association
Fire Drills	The facility failed to meet the provisions of the NFPA Life Safety Code by failing to conduct monthly fire drills for reach shift of personnel on a quarterly basis for two out of four quarters

Augusta House Statement of Deficiencies, 5/17/2019	
Deficiency Area	Expectation Not Met
Governing Body	The governing body failed to ensure the facility was maintained in good repair and provided a homelike environment
Program Monitoring and Change	The facility failed ensure that the specially constituted committee (Human Right Committee) included a community representative and a client representative
Client Bathrooms	The facility failed to ensure water temperatures did not exceed 110 degrees Fahrenheit in areas where clients have unsupervised access to water
Food and Nutrition Services	The facility failed ensure that a qualified dietician was employed
Food and Nutrition Services	The facility failed to follow the prescribed diet for one of three sampled clients
Fire Alarm System Notification	The facility was found to be out of compliance with the requirements for participation in Medicare/Medicaid Life Safety from Fire and the related NFPA Standard
Primary/Alternate Means for Communication	The facility failed to develop and maintain a current communication plan which includes alternate means for communicating with staff, Federal, State, tribal, regional, and local emergency management agencies in the event of limitations or cessation of operations to maintain the continuity of services to residents in the home

Augusta House Statement of Deficiencies, 2/26/2020	
Deficiency Area	Expectation Not Met
Drug Administration	The facility failed to ensure that medications were administered without error for medication administrations passes
Meal Services	The facility failed to ensure that appropriate portion sizes were served to clients in accordance with the amounts specified on the written menu
EP Testing Requirements	Facility staff failed to ensure they completed a full-scale all-hazards community-based emergency preparedness drill at least annually
Means of Egress	Facility staff failed to ensure the functioning of emergency lighting in several places as required by NFPA
Vertical Openings-Enclosure	Facility staff failed to ensure the joist between the floors could not be seen in the basement as required by NFPA
Corridors-Doors	Facility staff failed to ensure they protected all corridors by closing corridor doors when the area was not occupied as required by NFPA
Fire Drills	Facility staff failed to conduct and document evacuation drills every month with at least one drilled on every shift for every quarter as required by NFPA

Canterbury House Statement of Deficiencies, 8/7/2019	
Deficiency Area	Expectation Not Met
Governing Body	The governing body failed to ensure the facility was maintained in good repair and provided a homelike environment
Individual Program Plan	The facility failed to collect data according to the specified time frames in the Individual Habilitation Plan
Client Bathrooms	The facility failed to ensure water temperatures did not exceed 110 degrees Fahrenheit in areas where clients have unsupervised access to water
Food and Nutrition Services	The facility failed to follow prescribed diets for sampled clients
Dining Areas and Service	The facility failed to ensure that clients developed independent eating skills
Means of Egress Requirements	The facility failed to maintain one of three exit signs in the home and failed to maintain a designated means of escape, free of obstructions and impediments for instant use in the event of an emergency according to the guidelines of NFPA 101 Life Safety Code, 2012
Protection	The facility failed to maintain a smoke resistant barrier between the first floor and the basement as required by the NFPA 101 Life Safety Code, 2012 Edition
Fire Alarm System--Installation	The facility failed to ensure the fire alarm system complied with the requirements of NFPA 101 Life Safety Code, 2012 Edition and NFPA 72 National Fire Alarm and Signaling Code 2010 Edition
Corridors-Doors	The facility failed to ensure the doors were free of any impediments to the closing of the doors as required by the NFPA 101 Life Safety Code, 2012 Edition
Utilities-Gas and Electric	The facility failed to meet guidelines of the NFPA 101 Life Safety Code, 2012 Edition by allowing the use of power strips as a substitute for adequate wiring

Develop EP Plan, Review and Update Annually	The facility failed to provide a completed Emergency Preparedness Plan that met the requirements of the State Operations Manual Appendix Z-Emergency Preparedness of All Provider and Certified Provider Types

Canterbury House Statement of Deficiencies, 11/21/2019	
Deficiency Area	Expectation Not Met
Client Bathrooms	The facility failed to ensure water temperatures did not exceed 110 degrees Fahrenheit in areas where clients have unsupervised access to water
Protection	The facility failed to maintain a smoke resistant barrier between the first floor and the basement as required by the NFPA 101 Life Safety Code, 2012 Edition
Fire Alarm System--Installation	The facility failed to ensure the fire alarm system complied with the requirements of NFPA 101 Life Safety Code, 2012 Edition and NFPA 72 National Fire Alarm and Signaling Code 2010 Edition

Cameron Group Care, Inc. Statement of Deficiencies, 2/22/2019	
Deficiency Area	Expectation Not Met
Smoke Detection	The facility must meet the applicable provisions of either the Health Care Occupancies Chapter or Residential Board and Care Occupancies Chapters of the Life Safety Code NFPA
Corridors	The facility failed to ensure that a corridor wall would prevent the passage of smoke to a resident's sleeping room according to the guidelines of the NFPA
Dining Areas and Service	The facility must assure that each client eats in a manner consistent with his or her developmental level

Cameron Group Care, Inc. Statement of Deficiencies, 3/12/2020	
Deficiency Area	Expectation Not Met
Management of Inappropriate Client Behavior	The facility failed to establish program objectives or interventions in the Behavior Support Plan and in the Individual Habilitation Plan to manage inappropriate client behavior.
Physician Services	The facility failed to ensure laboratory examinations, determined necessary by the physician were completed on clients
Drug Administration	The facility failed to ensure that medications were administered without error for medication administrations passes
Drug Storage and Recordkeeping	The facility failed to ensure reconciliation of the receipt and disposition of all controlled drugs in schedule II through IV without error for medication administration passes
Hazardous Areas	The facility failed to ensure hazardous area doors contained self-closing devices
Fire Alarm System-Installation	The facility failed to properly install a complete fire alarm system in accordance with NFPA 72
Fire Alarm System-Testing and Maintenance	The facility failed to ensure 100% annual testing of the fire alarm system as required by NFPA 72

Sprinkler System-Supervisory Signals	Facility staff failed to ensure the sprinkler supervisory alarms were installed and monitored per NFPA 72

Southeast Missouri Residential Services Poplar Bluff Statement of Deficiencies, 9/13/2019	
Deficiency Area	Expectation Not Met
Individual Program Plan	The objectives of the individual program plan must be assigned projected completion dates
Dining Areas and Service	The facility must assure that each client eats in a manner consistent with his or her developmental level

Southeast Missouri Residential Services Sikeston Statement of Deficiencies, 2/7/2019	
Deficiency Area	Expectation Not Met
Management of Inappropriate Client Behavior	The use of systematic interventions to manage inappropriate client behavior must be incorporated into the client's individual program plan
Dining Areas and Service	The facility must assure that each client eats in a manner consistent with his or her developmental level

Lafayette Habilitation Center Statement of Deficiencies, 12/13/2019	
Deficiency Area	Expectation Not Met
Program Monitoring Change	The facility failed to ensure that the Qualified Intellectual Disabilities Profession reviewed and revised the objective identified in the Person-Centered Plan when clients had successfully completed the objectives
Drug Administration	The facility failed to ensure that medications were administered without error for medication administrations passes
Building Construction Type and Height	The facility failed to maintain walls free of penetrations to resist the passage of smoke
Emergency Lighting	The facility failed to itemize their emergency backup powered lighting devices, their statuses and their locations throughout the facility
Cooking Facilities	The facility failed to maintain the kitchen range hood in accordance with NFPA 96
Portable Fire Extinguishers	The facility failed to provide documentation to show monthly inspections of the fire extinguishers in accordance to NFPA 10
Corridors-Doors	The facility failed to maintain a corridor door to resist the passage of smoke and failed to ensure a corridor door was positive latching and had no impediment to closing in accordance to NFPA 101
Subdivision of Building Spaces-Smoke Departments	The facility failed to ensure smoke barriers were complete from an outside wall to an outside wall and from the floor to the roof deck
Fire Drills	The facility failed to conduct quarterly fire drills at various times on each shift for the months of November 2018 through November 2019
Electrical Equipment-Power Cords and Extension Cords	The facility failed to ensure electrical wiring was installed in accordance with NFPA
Electrical Equipment-Testing and Maintenance	The facility failed to perform and document the testing of the clients' room electrical receptacles that were not listed as hospital grade and failed to have a complete biennial electrical inspection of the facility's electrical system

Respite and Other Services

Access to respite services presents a challenge for many Missouri families. A need for respite surfaced in the NCI Adult Family Survey State Report 2018-2019 and Missouri's respite-related scores were largely below the average of NCI states. Only 15% of NCI respondents in Missouri were always able to get/use respite services when they needed them (compared to 33% across NCI states). In fact, most Missouri respondents (36%) said they were never able to get/use respite services when needed. When NCI respondents were able to access services, they were usually—but not always-- satisfied with the quality of those services. When compared to other NCI states, 5% fewer Missourians reported that they were always satisfied with respite care received (57% compared to 62%), although 10% more Missourians said they were usually satisfied (34% compared to 24%).[cxlvi] Additional data supports a desire for more respite resources: nearly 30% of NCI Adult Family Survey respondents stated that their family does not get the supports and services that they need and the most common additional service that families identified needing was respite (70%). Participants who completed the FACT DD Family Support Program in St. Charles, MO also identified short breaks/respite, as one of the most important issues to address.[cxlvii]

Figure 23. Satisfaction with Supports, NCI 2018-2019

Always able to contact support workers when they want:	Service and supports always change when family's needs change:
MO: 47% NCI: 59%	MO: 27% NCI: 41%
Always able to contact their case manager/service coordinator when they want:	**Support workers always speak in a way the family understands:**
MO: 48% NCI: 62%	MO: 70% NCI: 75%
Support workers always come and go when they are supposed to:	**Services are always delivered in a way that is respectful of the family's culture:**
MO: 51% NCI: 61%	MO: 71% NCI: 79%
If your family member does not communicate verbally, there are always support workers who can communicate with them	**Support workers have the right information and skills to meet your family's needs**
MO: 30% NCI: 33%	MO: 42% NCI: 50%

NCI also assess access and delivery of services and supports. Missouri ranked behind other NCI states for consistency of and satisfaction with services and supports (Figure 23). The smallest gap between NCI states and Missouri was with the indicator assessing support workers' ability to communicate with non-verbal clients (3%). The largest gap was 14%, which was the case both for services and supports changing with families' needs and being able to contact case managers. These data indicate that Missouri has room to improve with the delivery and quality of services to individuals and families with IDD.

Respite services were also mentioned in the Needs Assessment and listening sessions. Over half of Needs Assessment respondents indicated that respite services were important to them, but nearly 30% have unmet needs in this area. Missourians who identify as Hispanic/Latinx have a significantly higher unmet need for in-home respite care than those who do not identify as Hispanic/Latinx (50.0% compared to 28.8%, $p<.05$). When respondents were asked to gauge the services they would need in the next five years, more than half anticipated that respite would be important and more than a third identified indicated that they would need additional information and resources related to respite care in the future. Respondents who identified as a member of a racial or ethnic minority were more likely to

think that respite would be important in the future and were more likely to have additional needs related to respite (p>.05).

In the listening sessions, the topic of respite care often co-occurred with discussions about family mental health. Respite care was discussed as a crucial need for the well-being of the family, but participants identified a lack of respite care options. Families noted that when respite options are available, there are concerns about safety and whether complex care needs can be met by providers.

GOAL RATIONALE

Provide a rationale for the Council's goals *based on* the State Info, Portrait of the State & Analysis of State Issues & challenges from the CRA; including a rationale for strategies to address the goals.

- There should be a direct relationship between the goals and the needs identified based on the data collected and/or reviewed and feedback from a wide range of diverse stakeholders.
- The DD Act provides a broad mandate to address needs in the State, so it is essential that Councils prioritize their work.
- Not all the issues identified in the CRA can be addressed by the Council. Include a brief explanation of how the Council prioritized issues to be addressed in the Plan.

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