

**Survey Results from
a Study Tracking Impact of
the 55% Fee Cap and 56-hour
Family-Provided Home Care Limit on
Crash Survivors
Following the 2019
No-Fault Auto Insurance Reform**

September 2022

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Executive Summary

The Brain Injury Association of Michigan (BIAMI) commissioned this independent study by the Michigan Public Health Institute (MPHI) to document the impact of the fee structure changes in the 2019 Michigan no-fault auto insurance reform law that took effect on July 1, 2021, on auto crash survivors and their families. MPHI was chosen because of its expertise and depth of understanding of public health research. This report summarizes the results from two rounds of surveys of auto crash survivors, distributed in fall 2021 and in spring 2022, respectively.

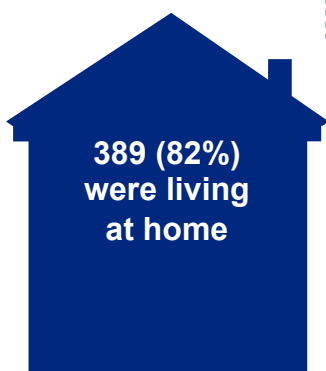
Results

Survey Participants

- 498 unique auto crash survivors (patients) participated in the surveys, including a cohort of 346 patients who participated in both surveys, and 152 who only participated in the first survey.
- 247 (50%) patients completed the surveys themselves, with the remainder completing the surveys with help of an authorized representative.
- 258 (52%) patients are male, 300 (60%) are over 45 years of age, 422 (85%) are white, 263 (53%) are single, 261 (52%) have at least some college education, and 272 (55%) have a household income of less than \$50,000.
- Patients were geographically diverse, residing in 56 of the 83 Michigan counties
- 380 (76%) patients have suffered traumatic brain injury from their auto crash, 320 (65%) have been living with their injuries for more than 10 years.

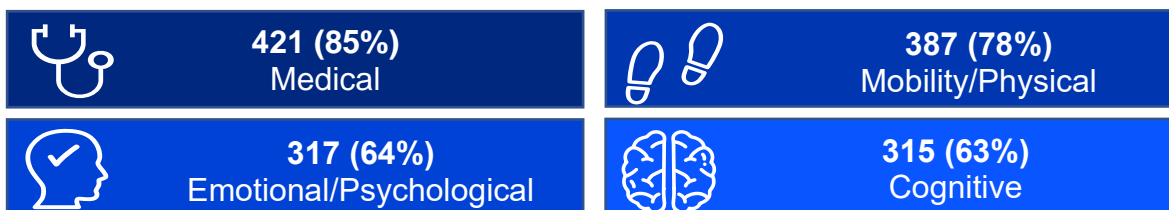
Before July 1, 2021

- 389 (82%) patients were living at home, 79 (17%) in a residential facility, and 4 (1%) in a skilled nursing facility. 251 (55%) had been living in their living arrangement for at least 10 years.



- 126 (27%) were living at home and receiving paid family-provided home care exclusively
- 111 (24%) were living at home and receiving commercial agency-provided home care exclusively
- 90 (19%) were living at home and receiving combined commercial agency and family-provided home care
- 62 (13%) were living at home without paid support
- On average, paid caregivers worked 145 hours per week to support the patient

- The following health needs were addressed before July 1, 2021



After July 1, 2021

- **456 (92%)** patients reported having been **affected** by either the 55% fee cap, the 56-hour limit, or others such as non-payment for services, delays in needed surgeries, medication, and equipment.
- **390 (78%)** patients reported **loss of services** such as physical or occupational therapy and transportation.
- **407 (82%)** patients have experienced an adversity, such as not being able to get medications or durable medical equipment (DME), increased family stress, depression, and despair.
- **256 (51%)** patients reported **having to use personal funds** to pay for services that they did not need to pay before.
- **42 (8%)** reported **hospitalizations** directly related to changes brought by the no-fault insurance reform, and 24 of them also reported an **average of 2.5 and up to 8 hospitalizations** since July 2021.
- **70 (20%)** patients reported in spring 2022 that they have applied for **Medicaid assistance** since July 2021. and 45 of them have enrolled.
- **153 (44%)** patients reported in spring 2022 that some of their **health needs are not currently being addressed**.
- On average, 126 weekly hours of attendant care are prescribed by a patient's doctor, and 109 weekly hours, or **87% of the prescribed hours**, are received by the patient. On average, patients receive **33 hours of un-paid family care** per week.

Comparing Before July 2021 and Spring 2022

- Among the cohort of 346 patients, there is a **universal reduction from before July 2021 to spring 2022** across all categories of the health needs addressed, level of care provided, rehabilitation services received, and other services, products, or accommodations received.
- Among the most received services before July 2021, there was a **39% reduction in therapy, 41% reduction in occupational therapy, and 40% reduction in transportation services** received in spring 2022.
- **16% more** patients are living at home with family-only support or without any support. **13% fewer** patients are living at home with agency-only or combined agency and family support.
- **77% more patients are unable to work due to disability, 43% fewer patients are employed full-time.**

About this Study

Limitations

The target patient population of this study are auto crash survivors in Michigan whose care were provided by no-fault auto insurance funding. However, MPHI does not have a mailing list of the target populations. The first survey in fall 2021 was distributed as a public link, sent to BIAMI's networks and their members by BIAMI and partners. The first survey respondents who provided contact emails were invited to participate in the second survey. The second survey was also distributed through a public link. There is no way to know whether the survey invitation reached all the auto survivors, and whether the respondents are representative of the target population.

MPHI Research Team

MPHI is a public-private partner with a variety of public health, government, and community organizations and is committed to conducting public health work based on strong scientific evidence and the needs of Michigan residents. This study is conducted by a team from MPHI's Center for Data Management and Translational Research (CDMTR), including Dr. Clare Tanner, director; Dr. Shaohui Zhai, Statistician; Dr. Issidoros Sarinopoulos, Senior Research Scientist; and Kayla Kubehl, Research Assistant.

Survey Results

Patient Demographics and Injury Information

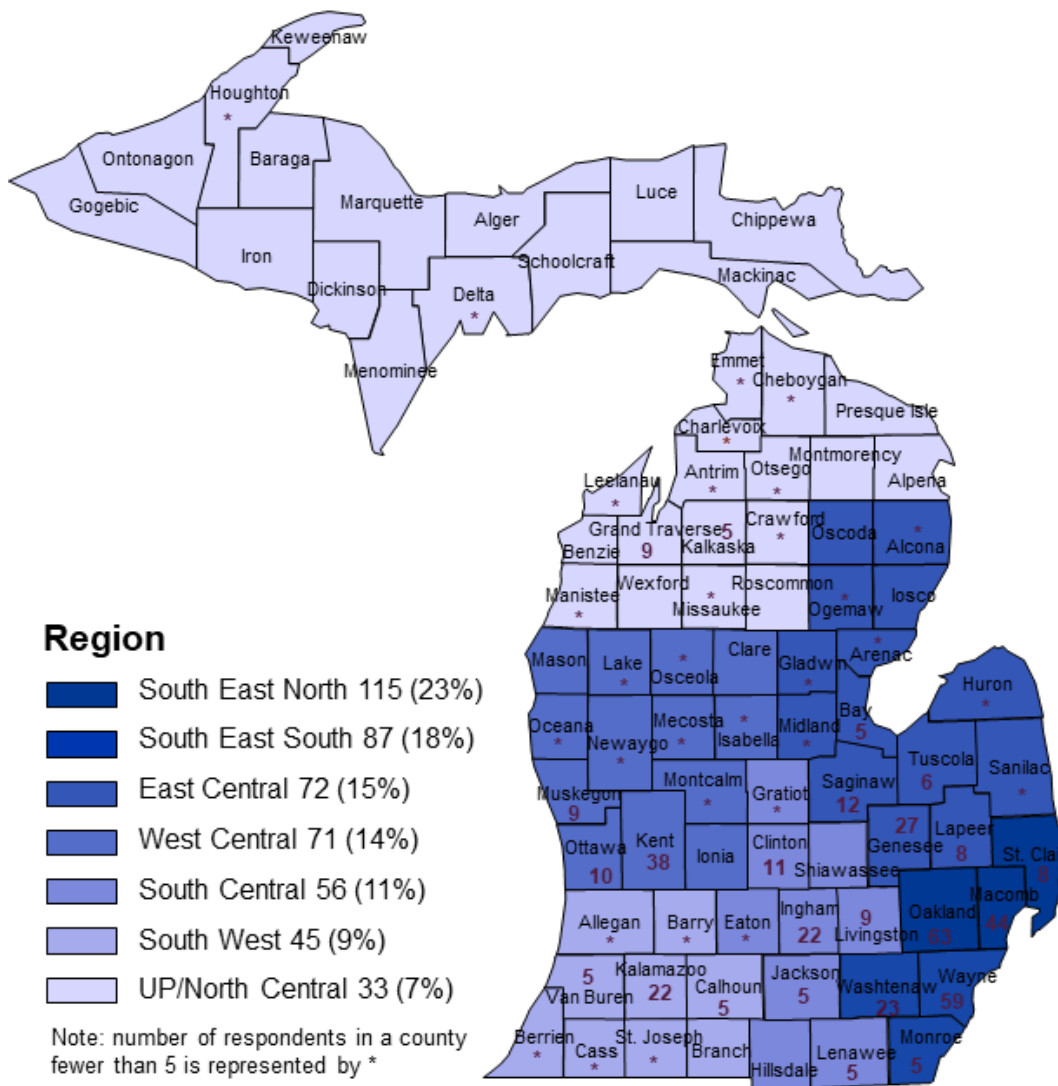
A total of 498 unique patients participated in the surveys. 247 (50%) of the patients filled out the surveys by themselves and the remainder were represented by parents/guardians in the case of minor patients or assisted by guardians/patient-authorized representatives in the case of adult patients needing assistance to complete the surveys.

Demographics of patients

	Frequency	%
<i>Age</i>		
<24	28	6%
25-34	67	14%
35-44	103	21%
45-54	108	22%
55-64	114	23%
65+	78	16%
<i>Gender</i>		
Female	234	47%
Male	258	52%
Not disclosed	5	1%
<i>Race</i>		
White	422	85%
African American	38	8%
Other race	26	5%
Not disclosed	27	9%
<i>Highest Degree</i>		
Less than high school	49	10%
High school diploma or equivalent	155	31%
Vocational or technical training	30	6%
Some college	135	27%
Bachelor's degree	82	17%
Master's degree or above	44	9%
<i>Household Income</i>		
Less than \$25,000	188	38%
\$25,000 - \$50,000	84	17%
\$50,000 - \$100,000	90	18%
More than \$100,000	31	6%
Not disclosed	101	20%
<i>Marital Status</i>		
Single	263	53%
Married or in a domestic partnership	135	27%
Divorced	64	13%
Widowed	21	4%
Other/Not disclosed	10	2%

Other patient information includes household size, health insurance coverage, county of residence, and court-appointed guardianship and conservatorship.

- The average household size is 2, with an average of 1.6 adults and 0.4 children. The higher income households reported higher numbers of adults and children, and the lowest income households reported lowest numbers of adults and children
- 304 (61%) patients are on Medicare, 185 (37%) are on Medicaid, 142 (29%) have private/commercial coverage, and 23 (4%) have no medical insurance.
- 479 (96%) patients live across 56 of the 83 Michigan counties, 19 live outside of Michigan or have no location data. The map below shows the distribution of the Michigan patients across counties and regions (Michigan Trauma Regions).
- 265 (53%) do not have a court-appointed guardian. 178 (36%) have a family member as a court-appointed guardian, 37 (7%) have a professional as a court-appointed guardian. 145 (29%) have a court-appointed conservator.



Information about the Injury

Respondents were asked about the length of time since the car crash that led to the patient's injury(s) as well as the resultant ongoing impacts from the injury(s).

- Traumatic brain injury (380, 76%), spinal cord injury (162, 33%), and back injury (131, 26%) are the most common ongoing health impacts.
- 320 (65%) patients have been living with their injuries for more than 10 years.

Years since injury and ongoing health problems

	Frequency	%
<i>Time since injury (n=490)</i>		
More than 20 years	183	37%
11-20 years	137	28%
6-10 years	81	17%
3-5 years	58	12%
1-2 years	27	6%
Less than a year	4	1%
<i>Ongoing health problems (n=498)</i>		
Traumatic Brain Injury	380	76%
Spinal Cord Injury	162	33%
Back Injury	131	26%
Limb or hip injury	44	10%
Vision Problems	30	7%
Organ Damage	18	4%
Pain (including headaches)	12	3%
Mobility Problems	12	3%
Amputation	12	3%
Hemiparalysis	10	2%
Mental Health	8	2%
Speech and/or Communication	6	4%
Seizures	6	1%
Nerve Damage	6	1%
Psychological Problems	4	1%
Hearing Problems	4	1%
Memory Problems	3	1%

Before the 55% Fee Cap and 56-Hour Limit Taking Effect on July 1, 2021

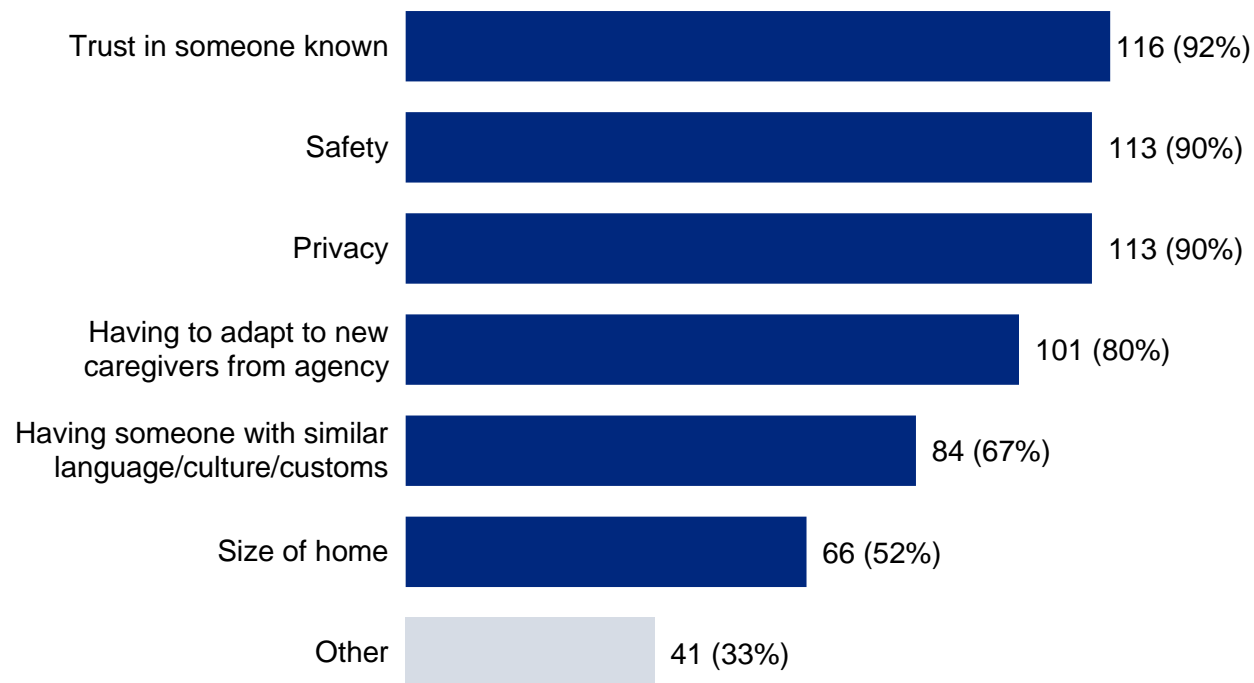
To establish a baseline, the surveys asked about patients' life circumstances before the 55% fee cap and 56-weekly-hour limit on family-provided home care under Michigan's no-fault insurance law reform took effect on July 1, 2021.

- 152 (31%) patients were employed in some capacity (full-time, part-time, or/and through a supported work program).
- 389 (82%) were living at home. Of those, 327 (84%) had paid home support, 62 (16%) were without paid home support
- 251 (55%) patients had been in the reported living arrangement for at least 10 years before July 1, 2021.

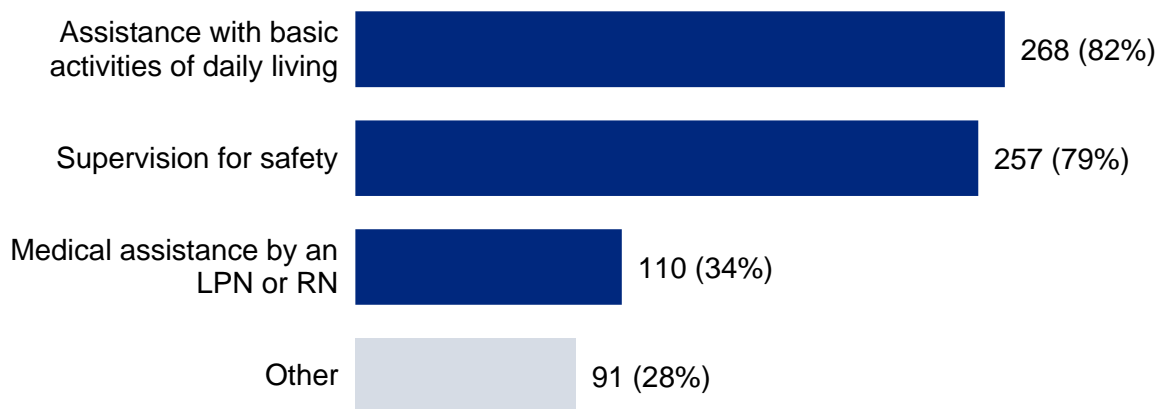
Employment status, primary living arrangement, and health needs addressed before July 1, 2021

Employment Status (n=498)	Frequency	%
<i>Employed</i>	152	31%
Full-time	68	14%
Part-time	41	8%
Employed through a supported work program	50	10%
<i>Unable to work due to disability</i>	154	31%
<i>Unemployed and looking for work</i>	16	3%
<i>In school</i>	31	6%
<i>Retired</i>	64	13%
<i>Other</i>	110	22%
Living Arrangement (n=472)		
<i>Living at home</i>	389	82%
with support from paid family	126	27%
with support from an agency	111	24%
with combined support from paid family and agency	90	19%
Independent without in-home support	62	13%
<i>Residential treatment facility/group home</i>	44	9%
<i>Semi-independent living through a residential program</i>	35	7%
<i>Skilled nursing facility</i>	4	1%
Length of Time in Living Arrangement (n=455)		
<i>More than 15 years</i>	175	38%
<i>10-15 years</i>	76	17%
<i>5-10 years</i>	86	19%
<i>2-5 years</i>	84	18%
<i>Less than 2 years</i>	34	7%
Health Needs Addressed (n=498)		
<i>Medical</i>	421	85%
<i>Mobility/Physical</i>	387	78%
<i>Emotional/Psychological</i>	317	64%
<i>Cognitive</i>	315	63%
<i>Other</i>	83	17%

Reasons rated as very important for choosing to have in-home care provided exclusively by family, before July 1, 2021 (n=126)



Level of care provided for patients who were living at home with support from family, agency, or combined family and agency, before July 1, 2021 (n=327)

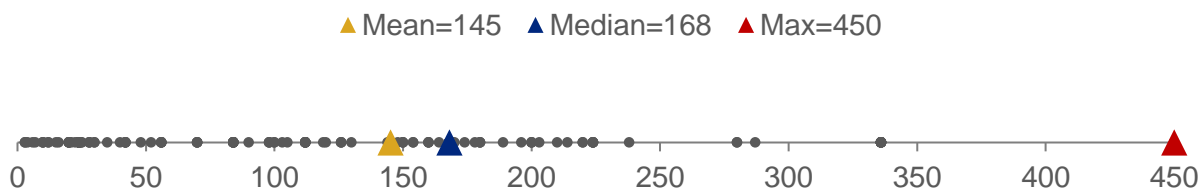


Home Care Hours before July 1, 2021

Among patients who were living at home with paid support, either by family, agency, or combined family and agency:

- 298 (94%) patients were receiving home care 7 days a week.
- 239 (75%) patients were receiving home care 24 hours a day.
- 258 (83%) patients were receiving total weekly care hours exceeding the 56-hour cap, ranging from 3 to 450 hours (when multiple caregivers were needed), with a median of 168 hours (equivalent to 24 hours a day and 7 days a week) and an average of 145 hours.
- Of the 126 patients who were supported by family exclusively, 98 (78%) were receiving weekly care hours exceeding the 56-hour cap.
- Of the 90 patients who were supported by combined family and agency, the portion of total weekly hours provided by the agency was 54%, 12 hours per day 6 days per week, on average.

Total weekly caregiver(s) hours supporting patient before July 1, 2021 (n=312)

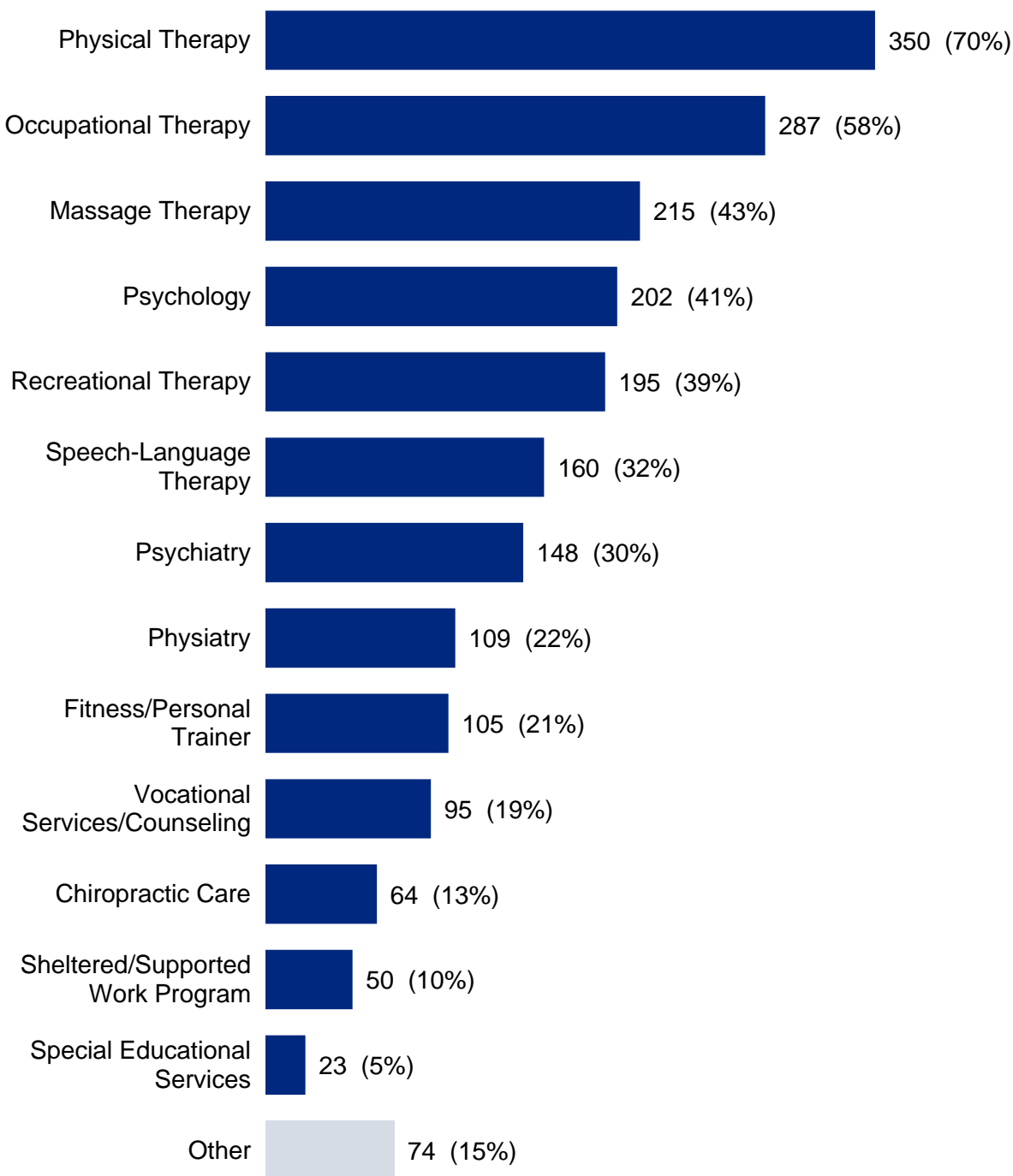


Services Provided before July 1, 2021

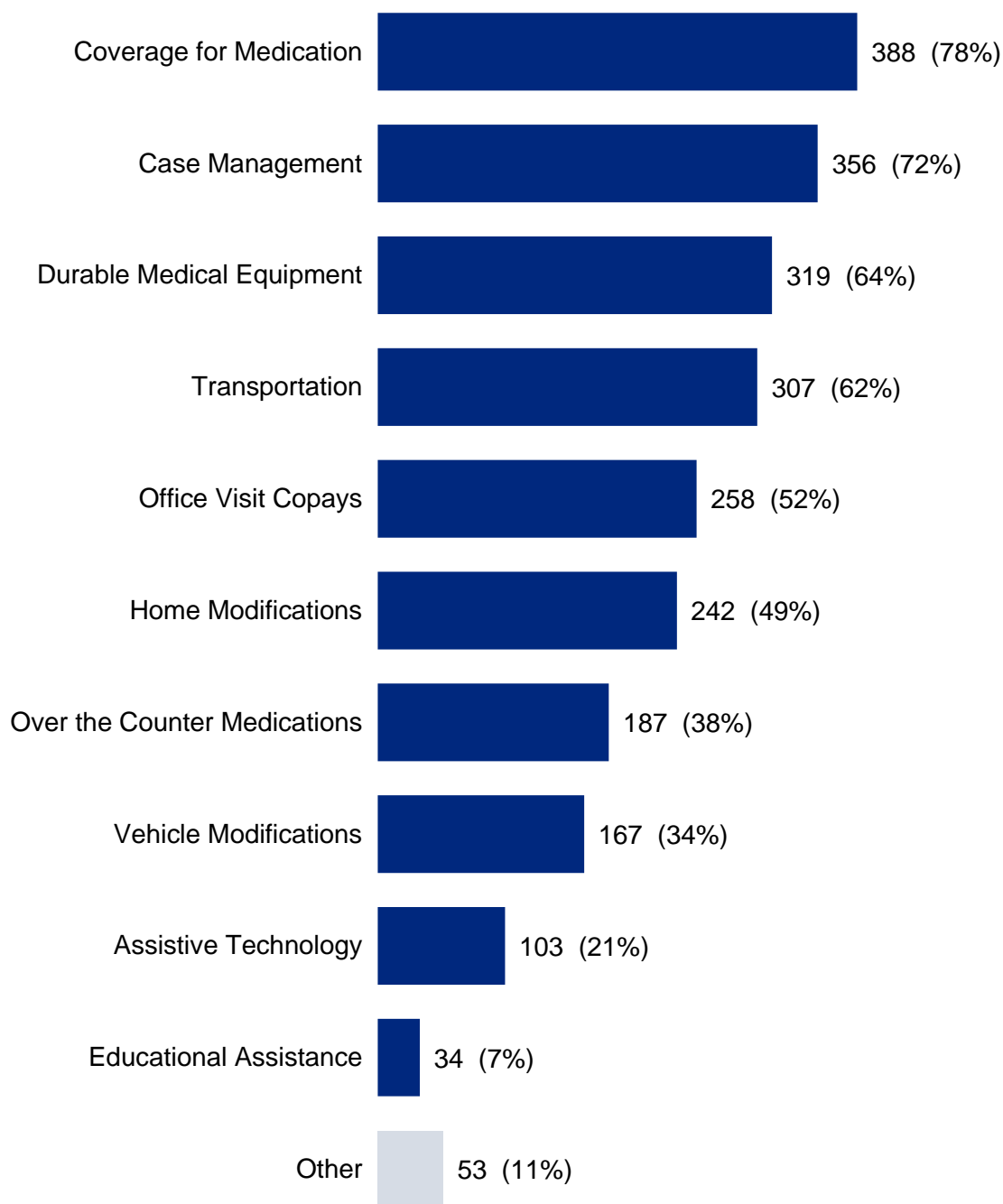
Respondents reported on what rehabilitation services, other services, products, or accommodations patients were receiving before July 1, 2021, that were covered by their no-fault insurance company.

- The most frequently reported rehabilitation service was physical therapy (350, 70%).
- The most frequently reported other services/products/accommodations was coverage for medication (388, 78%).
- Reported in the other rehabilitation category included pain management (e.g., Botox or acupuncture), hydrotherapy, vision therapy, dental care, and other specialized therapies.
- Reported in the other category for other services/products/accommodations included recreational therapy, orthodontics, medications, and assistive technology.

Rehabilitation services being provided before July 1, 2021 (n=498)



**Other services, products or accommodations provided before July 1, 2021
(n=498)**

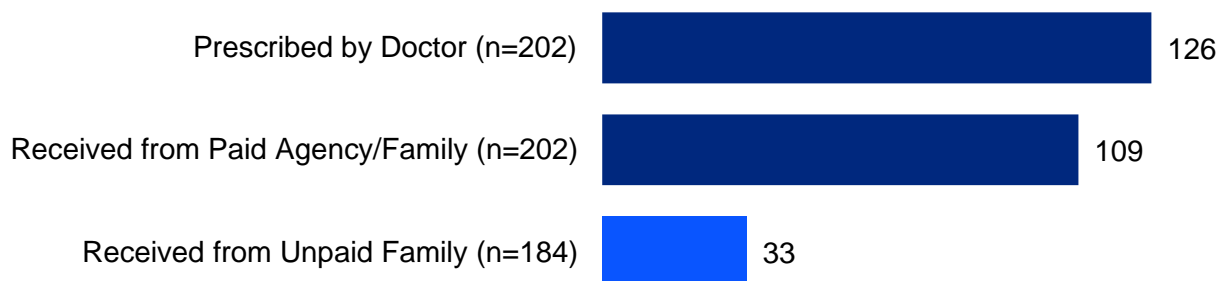


After the 55% Fee Cap and 56-Hour Limit Taking Effect on July 1, 2021


















Almost all respondents (445, 91%) reported that they were aware of the provider 55% fee cap and 56-weekly-hour limit on paid family-provided home care under Michigan's no-fault insurance reform that took effect on July 1, 2021.

- 379 (76%) reported having been affected by the 55% fee cap, and 238 (48%) reported having been affected by the 56-hour limit.
- 456 (92%) reported having been affected by either the 55% fee cap, the 56-hour limit, or others such as non-payment for services, delays in needed surgeries, medication, and equipment.
- 390 (78%) reported that they have lost services. The top three services lost are physical therapy (186, 37%), hours of agency-provided home care (142, 29%), and transportation (139, 28%).
- 407 (82%) reported having experienced adversities. The top four adverse experiences are: increased feelings of anxiety, depression, or despair (331, 66%), lack of progress in rehabilitation (172, 35%), increased health and medical problems (164, 33%), and increased behavioral problems (158, 32%).
- 42 (8%) reported hospitalizations directly related to changes brought by the no-fault insurance reform. Of those, 24 also reported at the second survey the number of hospitalizations since July 1, 2021. The reported average is 2.5, ranging from 1 to 8 hospitalizations.
- 292 (59%) reported experiencing financial hardship, 256 (51%) reported having to use personal funds to pay for services that they did not need to pay before, and 126 (36%) reported having to rely on unpaid help from family, friends, or neighbors.
- 70 (20%) of those who responded at the second survey reported having to apply for Medicaid programs. Of those, 45 (64%) have since enrolled in Medicaid programs that they did not need before July 2021.
- On average, 126 weekly hours of attendant care are prescribed by a patient's doctor, 109 weekly paid hours of care (87% of the prescribed hours) and 33 weekly hours of un-paid family care are received by the patient.

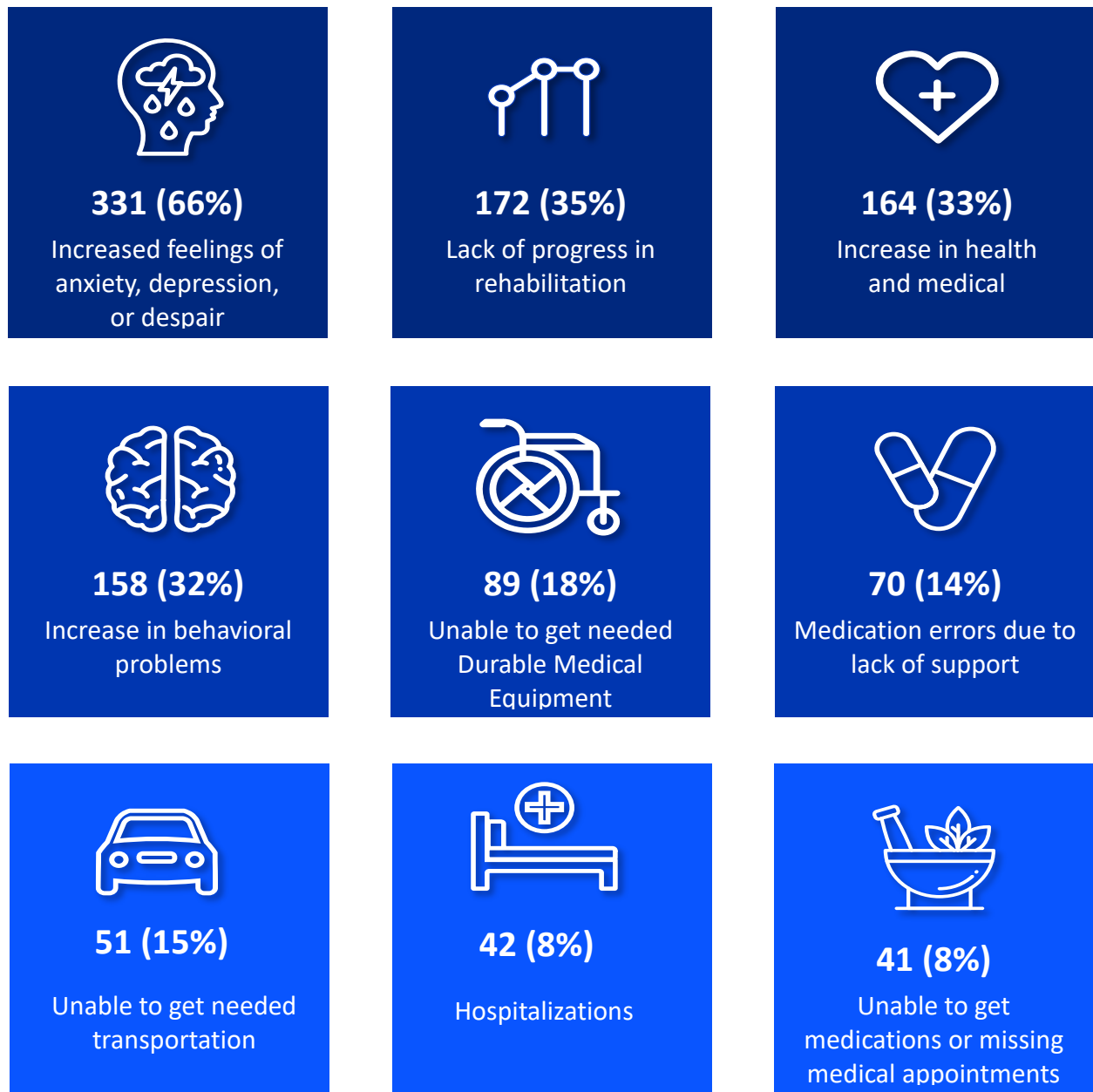
Average weekly hours of attendant care currently prescribed by doctor and received by patient, reported in spring 2022



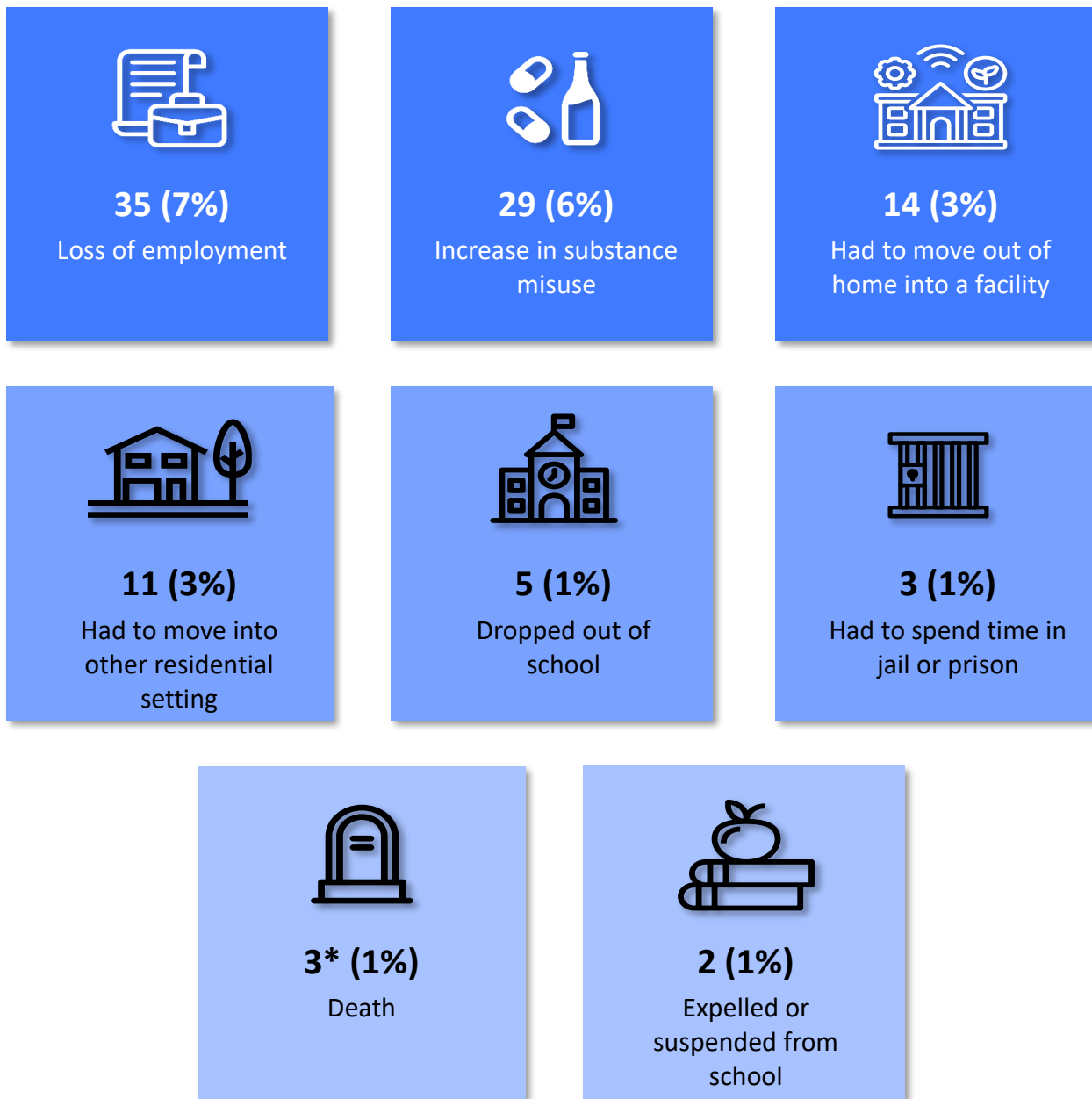
Services lost since July 1, 2021, due to the changes (n=498)

	Loss of physical therapy	186 (37%)
	Reduced hours of home care by agency	142 (29%)
	Loss of transportation	139 (28%)
	Gaps in support/care	133 (27%)
	Family/friends are no longer able to provide care	117 (24%)
	Loss of massage therapy	64 (19%)
	Loss of occupational therapy	50 (15%)
	Loss of recreational therapy	48 (14%)
	Lost home care altogether	45 (13%)
	Loss of Durable Medical Equipment	44 (13%)
	Family-owned agency nursing limited to 56 h/week	60 (12%)
	Loss of medication coverage	27 (8%)
	Loss of medical supplies	36 (10%)
	Loss of speech-language therapy	22 (6%)
	Loss of special educational services	21 (4%)
	Discharged from a residential treatment facility	9 (2%)
	Discharged from a supported living program	7 (1%)

Adversities experienced since July 1, 2021, due to the changes (n=498)

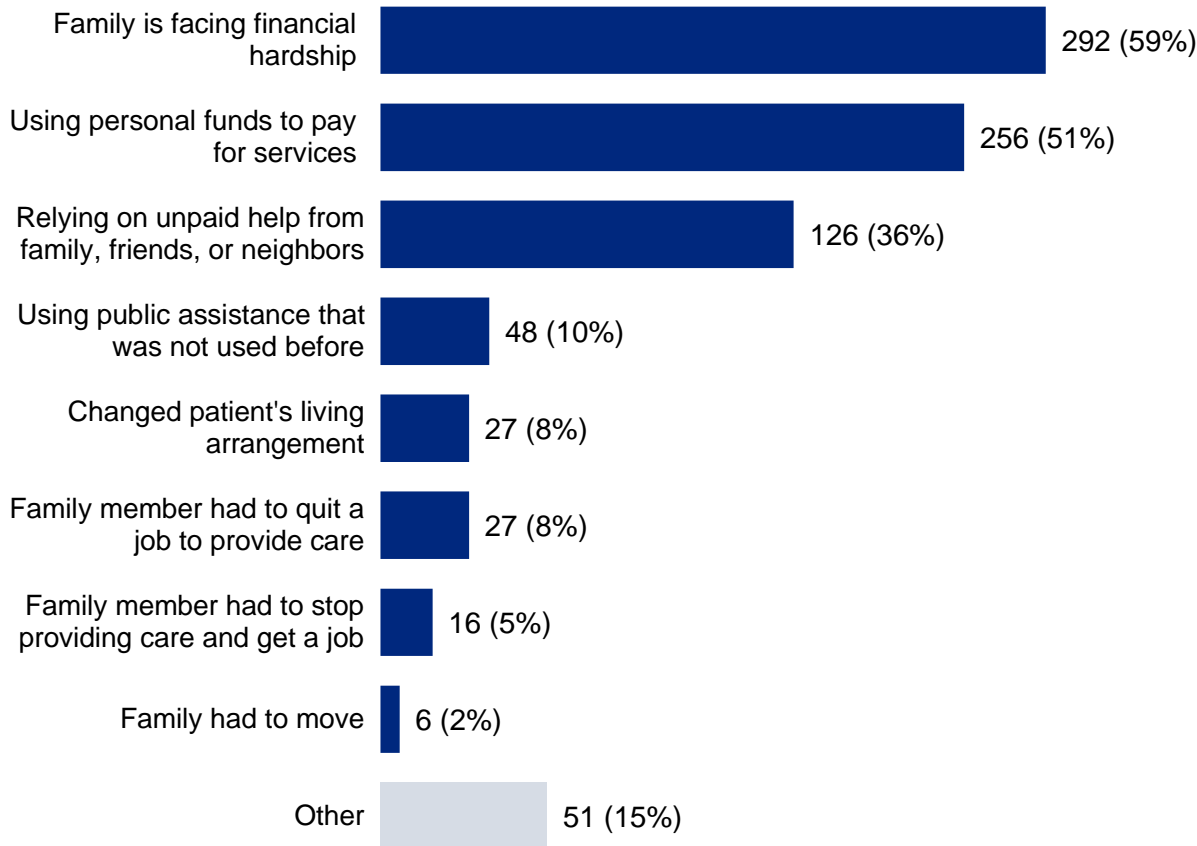


Adversities experienced since July 1, 2021, due to the changes (continued)

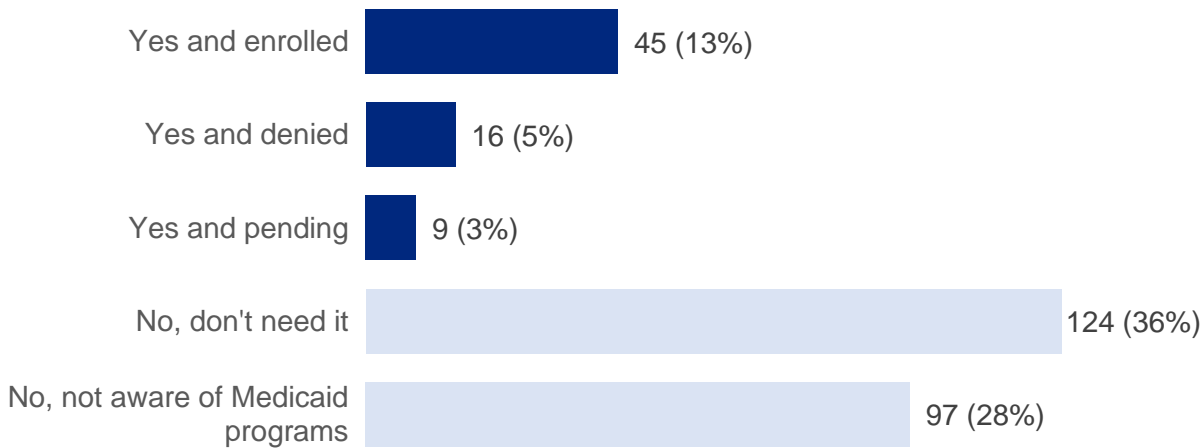


* Not included here are 3 more deaths since the first survey that the research team learned about during the phone calls to the second survey non-respondants who participated in the first survey.

Financial and family impacts by the changes since July 1, 2021 (n=498)



Patients who applied for Medicaid programs since July 1, 2021, reported in spring 2022 (n=346)



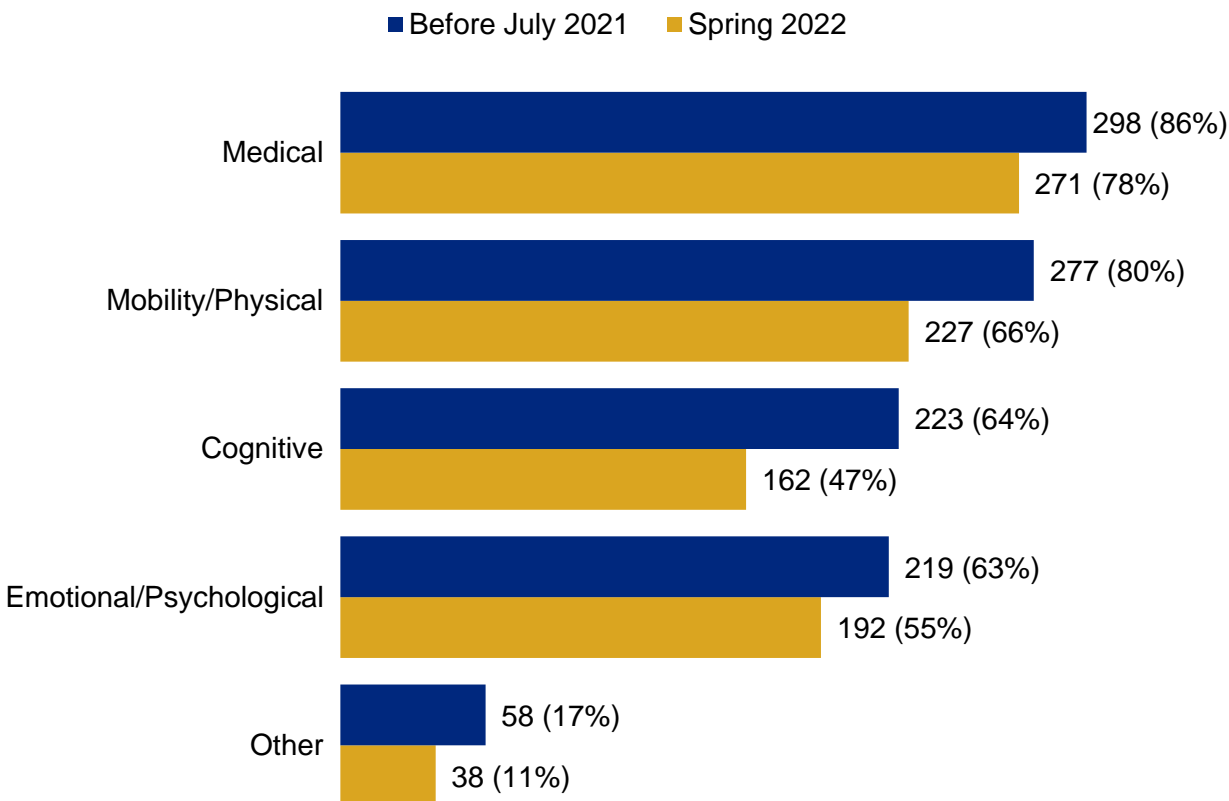
Comparing Before July 2021 and Spring 2022

This section tracks the same 346 patients who have data for both the baseline (before July 2021) and the time of the second survey in spring 2022, reporting on changes in health needs addressed, living arrangement, level of care received, rehabilitation services received, other services/products/accommodations received, and employment status.

Health Needs Addressed

- In all categories of health needs that were being addressed before July 2021, fewer patients reported in spring 2022 that these needs are being addressed.
- The largest reduction is 17 percentage points in cognitive needs.
- 153 (44%) patients reported currently having unmet health needs, including physical therapy, recreational therapies, attendant care, doctor appointments, medication, living support, cognitive therapy, occupational therapy, transportation, speech therapy, pain management, durable medical equipment, and mental and social needs. Lesser mentioned unmet needs included case management, memory, vision care, dental care, and other specialized therapies.

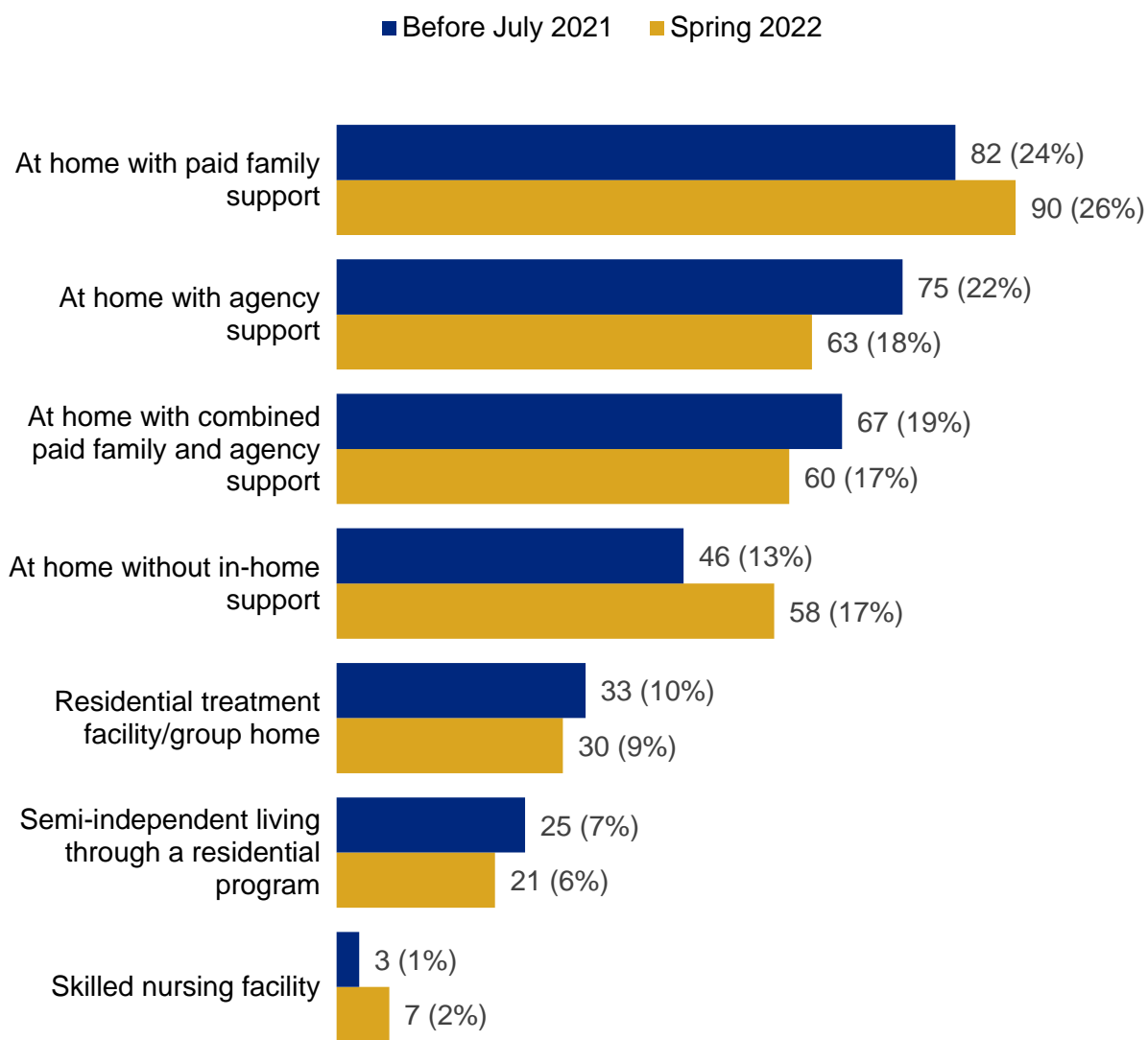
Health needs addressed before July 2021 and in spring 2022 (n=346)



Living Arrangements

- Compared to before July 2021, more patients are currently living at home with family support exclusively (82, 24%) vs. (90, 26%).
- Compared to before July 2021, more patients are currently living at home without in-home support (46, 13%) vs. (58, 17%).
- 3 (1%) patients were discharged from residential treatment facility/group home, 4 (1%) patients were discharged from semi-independent living through a residential program.
- 4 (1%) patients were moved to a skilled nursing facility.

Living arrangement before July 2021 and in spring 2022 (n=346)

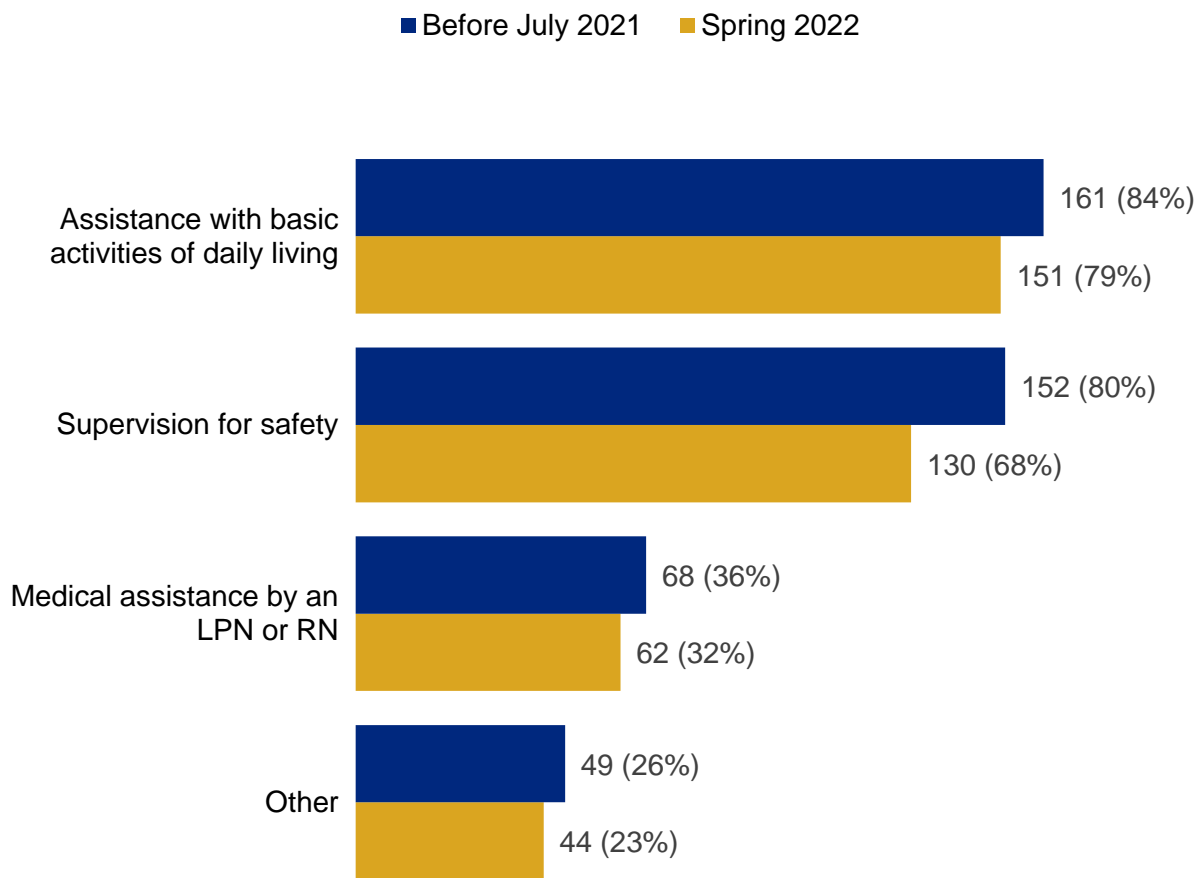


Level of Care Provided at Home

Among the 191 patients who were living at home with support before July 1, 2021 and are still living at home with support in spring 2022:

- In all categories of level of care received at home before July 2021, fewer patients reported that they are currently receiving these cares at the second survey.
- 161 (84%) patients received assistance in basic activities of daily living before July 2021, 151 (79%) are currently receiving this care, a reduction of 5 percentage point.
- 152 (80%) patients received supervision for safety before July 2021, 130 (68%) are currently receiving this care, a reduction of 12 percentage points.

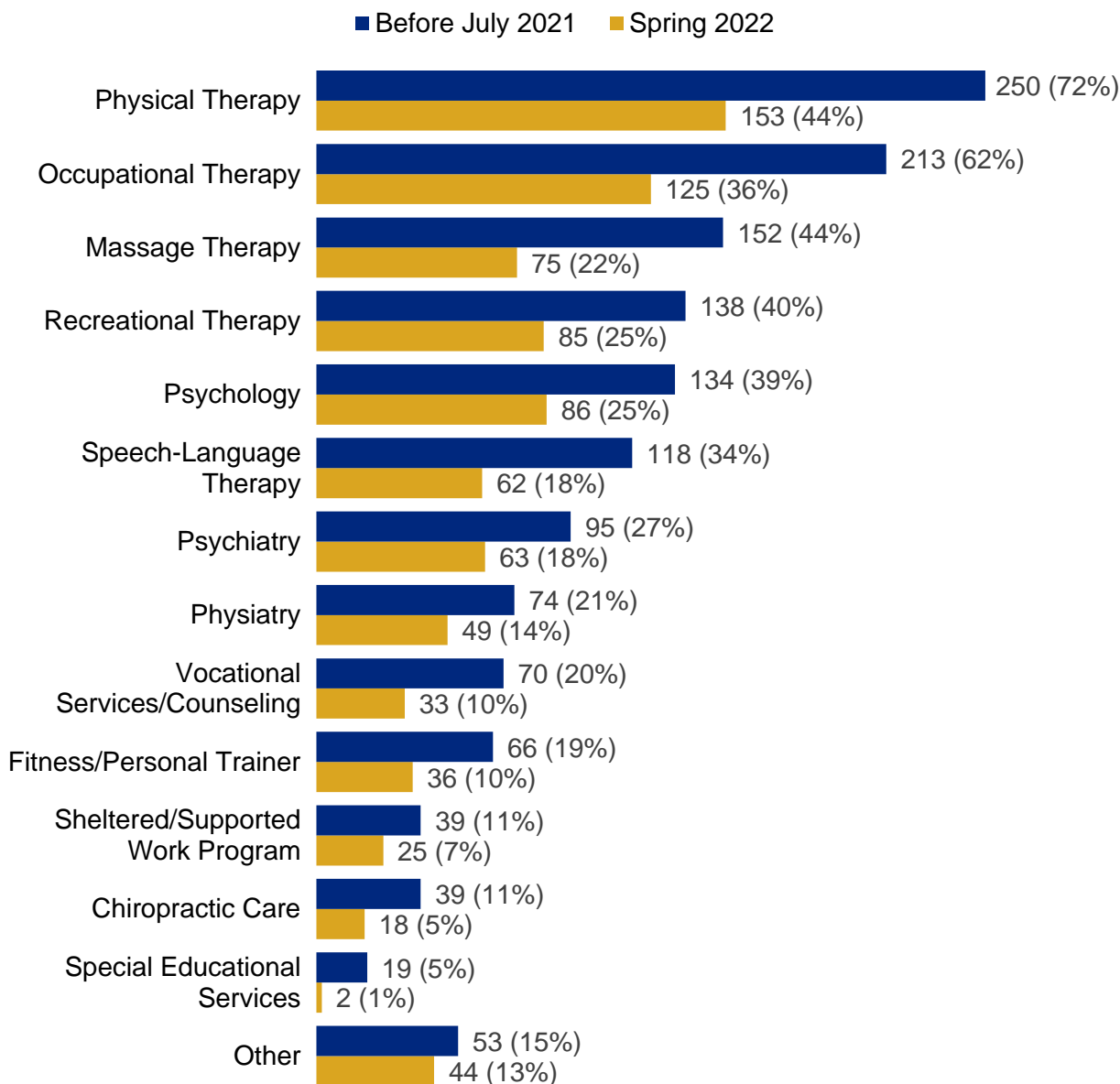
Level of care before July 2021 and in spring 2022 (n=191)



Rehabilitation Services

- In all categories of rehabilitation services received before July 2021, fewer patients reported that they are currently receiving these services.
- 250 (72%) were receiving physical therapy before July 2021, 153 (44%) are receiving currently, a reduction of 28 percentage points.
- 213 (62%) were receiving occupational therapy before July 2021, 125 (36%) are receiving currently, a reduction of 26 percentage points.
- 152 (44%) were receiving massage therapy before July 2021, 75 (22%) are receiving currently, a reduction of 22 percentage points.

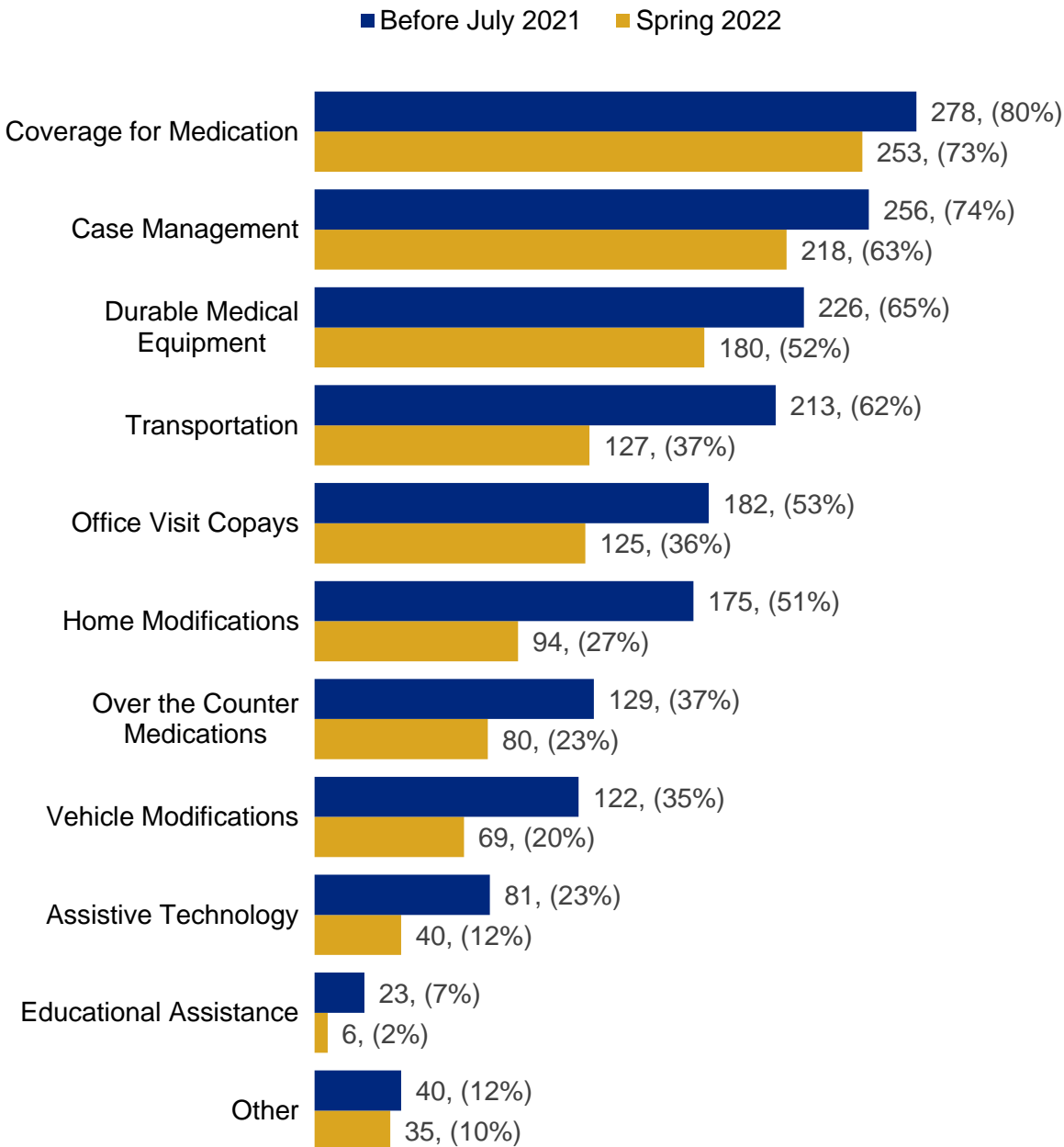
Rehabilitation services received before July 2021 and in spring 2022 (n=346)



Other Services, Products, and Accommodations

- In all categories of other services/product/accommodations received before July 2021, fewer patients reported that they are currently receiving them.
- Transportation services had the largest reduction of 25 percentage points, from 213 (62%) before July 2021 to 127 (37%) in spring 2022.

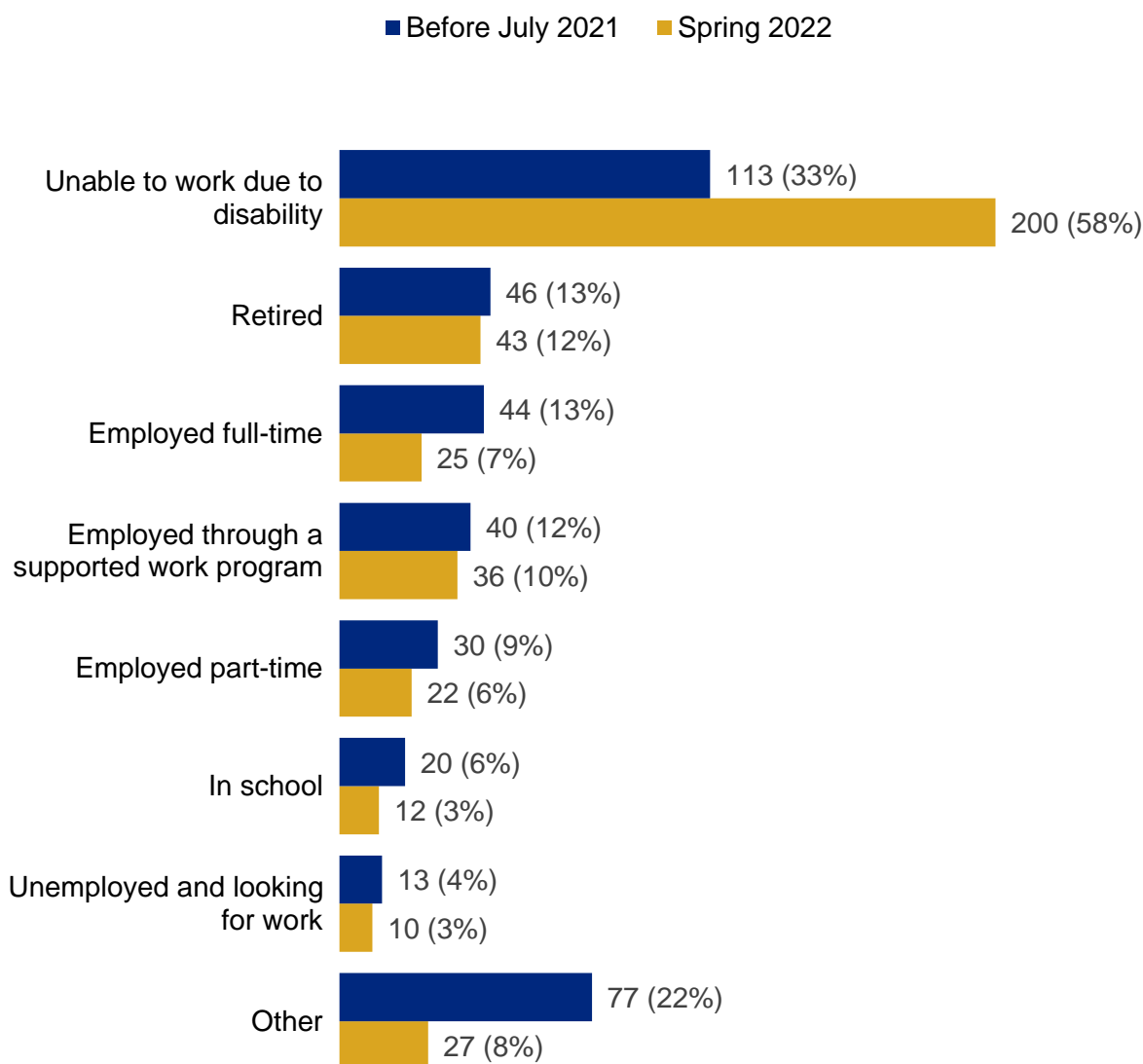
Other services/products/accommodations received before July 2021 and in spring 2022 (n=346)



Employment Status

- The number of patients reported unable to work due to disability increased from 113 (33%) before July 2021 to 200 (58%) in spring 2022, an increase of 25 percentage points.
- The unique number of patients reporting any employment (full-time, part-time, or through supported work programs) decreased from 108 (31%) before July 2021 to 78 (23%) in spring 2022, a decrease of 8 percentage points.
- The Other category includes vocational rehabilitation program, freelance work, and seasonal work.

Employment status before July 2021 and in spring 2022 (n=346)



Patient & Family Perspectives

Respondents were asked to describe in their own words what these changes meant to them. 219 respondents provided an answer in the first survey and 196 respondents provided an answer in the second survey.

Not included in the following table but worth mentioning are sentiments obtained through the survey reminder phone calls from some of the first survey respondents who chose not to participate in the second survey. They expressed discouragement with the ability to change the law, did not feel their voices would be heard or would make a difference, and feared they would have less services covered if they spoke out about the law changes.

Loss of services or care	<i>“Lost massage therapy that reduces the pain and contracture in the left foot. These massage therapies reduce the number of Botox shots needed to keep the foot flat to provide walking without pain and reduce the abnormal gait.”</i>
Increase in stress	<i>“The stress of the entire situation and what it could mean if the law isn’t fixed is a heavy burden that we shouldn’t have to bear.”</i>
Financial burden	<i>“Family is exhausted, and this has created a tremendous strain on our family, marriage, and finances. We have paid thousands of dollars out of pocket as few services will deal with no-fault or [insurance company’s] insurance due to reduced payments or slow payments.”</i>
Lack of caregivers	<i>“It has been an absolute disaster. Our daughter has regressed due to reductions in therapy, finding nurses and aides to assist in care is almost impossible because the agencies cannot pay them a competitive wage. Our aide agency is the last standing in our areas and if they go bankrupt, which they are close to doing, we have no other options as our daughter needs 24-hour care.”</i>
Decline in mental health (increased anxiety, depression, and PTSD)	<i>“My mental wellbeing is shot. I feel I’ve been given a ‘death sentence’ that will be executed in a couple years when I run out of my personal funds.”</i> <i>“They have made me want to give up.”</i>

Originally promised benefits	<i>“Those car accident victims prior to 7-1-21 should be grandfathered in for the benefits they signed a contract for. Now it seems that the insurance companies can make changes any time they want. The home care we receive can change negatively very quickly that would put our family in financial jeopardy. The Michigan legislature should do the right thing and correct the problems.”</i>
Selling property to survive	<i>“We can only last another four to six months before we will have to sell our home to survive.”</i>
Non-payments	<i>“Every day I am nervous and concerned that I will soon lose my 24-hour nursing care due to lack of adequate reimbursement to the agency providing my care. They will not be able to carry on business with this rate of non-payment.”</i>
Increased transportation issues	<i>“With the rate of inflation and the increase cost of gas, and wear and tear on the car, the mileage rate should have been increased instead of decreased.”</i>
Deteriorating health	<i>“My son is receiving the most basic services required for his safety and wellbeing, but he is consistently deteriorating physically and mentally since 7/1/21. And the facility continues to state he must be removed to another facility because they cannot continue to staff his needs. So far, I have been able to maintain his position only because I refuse to remove him to an unsafe facility.”</i>
Needing more care than receiving	<i>“The other issue is that family is limited to how many hours we are able to care for [him], since the law change it went from unlimited to 56 hours. Before the law change, we had 6 family members helping (117 hours) and now we have had to drop down to about 90 hours (34 hours unpaid). [He] is 32-7 care total. We asked our insurance agency for an increased attendant care contract and we were denied without reason.”</i>
Taking legal action	<i>“My wife is a plaintiff in a major lawsuit to overturn the law.”</i>

<p>Inadequately equipped facilities to deal with car crash survivors</p>	<p><i>“My wife is under constant stress & fear of losing my caregivers because she can't take care of me alone and needs to work outside the home. I am afraid I will end up dying if I have to go to a nursing home.”</i></p> <p><i>“I am a nervous wreck wondering what will happen to me. Nursing homes are 1 nurse to 40 patients. They can't possibly take care of that many patients properly. I am not eating well and feel like I am going to have a nervous breakdown.”</i></p>
<p>Loss of progress</p>	<p><i>“My life has turned upside down since July 01-2021. Notable gains I had made during the various treatments have significantly decreased since the change in the no-fault law.”</i></p>
<p>Home modification or durable medical equipment</p>	<p><i>“He has to pay out of his pocket for durable equipment.”</i></p>
<p>Worse quality of life</p>	<p><i>“I've learned from personal experiences that long-term care for someone with a spinal cord injury requires specialized care. Without it, quality of life and well-being becomes compromised.”</i></p>
<p>Poor communication from the insurance company or DIFS</p>	<p><i>“[Insurance company] stated nothing will change after I had an evaluation that determined I needed the hours I was getting because of my injury but eventually they changed from 112 hours per week to 56 hours and reduced my hourly rate from 16.25 to 13\$. They told me to send in any documentation to support my needs and every time I send them what they ask for I never hear anything back only that they're waiting.”</i></p>
<p>Wanting family to provide care</p>	<p><i>“The laws have forced me into receiving care from strangers and non-family members for my personal and embarrassing needs. It makes me extremely uncomfortable and is causing me distress and mental anguish.”</i></p>
<p>Increased anger</p>	<p><i>“But because her sister needed to get a job due to the cut in hours of pay from no-fault, this impacted [patient]'s behavior, from somewhat calm to outright anger and hostility towards me her now primary care giver. She hates the instability of not knowing who will take her to her doctor's appointment, or care for her.”</i></p>

Cutting mileage for case worker	<i>“The insurance company is threatening stopping mileage for my case worker. She said she will continue to see me if they do this.”</i>
Hospitalization or calling for ambulance	<i>“So now we are calling for ambulance to pick him up to go to the hospital to have his blood work done. That's cost more than if they would pay for RN to come to the house.”</i>
Unpaid family caregiver hours	<i>“My husband is now providing many more hours of my care than he was before the law changed, but is only being paid for 56 hours, at a rate that is not adequate to cover our expenses. Yet he is not able to work at a regular job to make up for the lost income because I don't have enough reliable agency caregivers to provide me help while he would be working. As a result, we have seen our savings dwindle drastically, and we worry about paying our mortgage and other bills.”</i>
Signed a new contract	<i>“I signed a contract that left my family paid attendant care as is, but it is only for 5 years. My concern is what will happen after the 5 years is up.”</i>
Death	<i>“He died of a heart attack on October 25, 2021. After his death, his family doctor reported that he had given him a physical exam about a month earlier. The doctor said that looking back on his records, he could find no reason to suspect any heart difficulties, and he just shook his head when asked what he thought had happened. His parents and caretaker brother believe the stress of not being able to pay for caretakers was the underlying cause of his death. After the new rules were enforced, our normally cheerful child went into a, 'funk,' with comments like: 'I'm just a burden.'; 'I'm ruining everybody's life now,'; 'You'd be better off if I was dead.' Here's the comment that brings tears to my eyes as I type it for this report: 'What can I do now, Dad?'”</i>
Worried to speak out	<i>“I want to complain but I don't want to mess up what we still have provided.”</i>

Methodology

Survey Development

The Auto Crash Survivors Surveys were collaboratively developed by MPHI and BIAMI. The surveys can be completed by either the adult patients themselves, by their parents/guardians in cases of minor patients, or by guardians/patient-authorized representatives if adult patients needed assistance in completing the surveys. Survey questions asked about patients' health status, living arrangements, and services received before and after the fee changes in the no-fault auto reform that took effect in July 2021, and some demographic information. The surveys also asked for some personally identifiable information, including respondent and/or patient names and contact email, and patient birthdate. MPHI researchers trained in survey development finalized all questions to ensure readability, clarity, and lack of bias.

Survey Implementation

The surveys were implemented in REDCap (Research Electronic Data Capture) by MPHI. REDCap is a secure web application for building and managing online surveys and databases. While REDCap can be used to collect virtually any type of data in any environment (including compliance with 21 CFR Part 11, FISMA, HIPAA, and GDPR), it is specifically geared to support online and offline data capture for research studies and operations.

MPHI and BIAMI pre-tested the surveys internally to make sure that the survey was implemented as designed. Additionally, a pilot test of the first survey with 15 patients was conducted between September 3 and 21, 2021.

Survey Distribution

The first survey was distributed by BIAMI to their members and networks, between September 29 and October 20, 2021. The invitation contained a public survey link to the survey, instructions on how to access, complete, save, submit, and print out a PDF copy of the survey, as well as how to contact MPHI for questions and assistance. Two rounds of reminders were sent out by BIAMI.

The second survey was distributed using two methods, one was by MPHI through email to the first survey respondents who provided contact emails, the other was by BIAMI and partners through a public link to their members and networks to recruit patients who did not participate in the first survey. The survey was distributed between March 9 and May 15, 2022. Three rounds of reminders were sent out during the distribution period. Additionally, the research team made phone calls to the non-responding patients who provided contact phone numbers in their first survey, encouraging and helping them to complete the second survey.

Internal Review Board Approval

MPHI's IRB operates following FDA regulations and is formally designated to review and monitor biomedical research involving human subjects with the authority to approve or disapprove research. This review is designed to ensure that researchers protect the rights and welfare of research participants. The IRB review assures that appropriate steps are taken to protect the rights and welfare of research participants. MPHI's IRB panel reviews research protocols and related materials to ensure protection of the rights and welfare of research participants.

The MPHI project team submitted a Human Participant Protections Application to the MPHI Institutional Review Board (IRB), and the approval of the project was granted on September 27, 2021.

This project was funded by BIAMI.

The study was conducted by MPHI with assistance from BIAMI.

