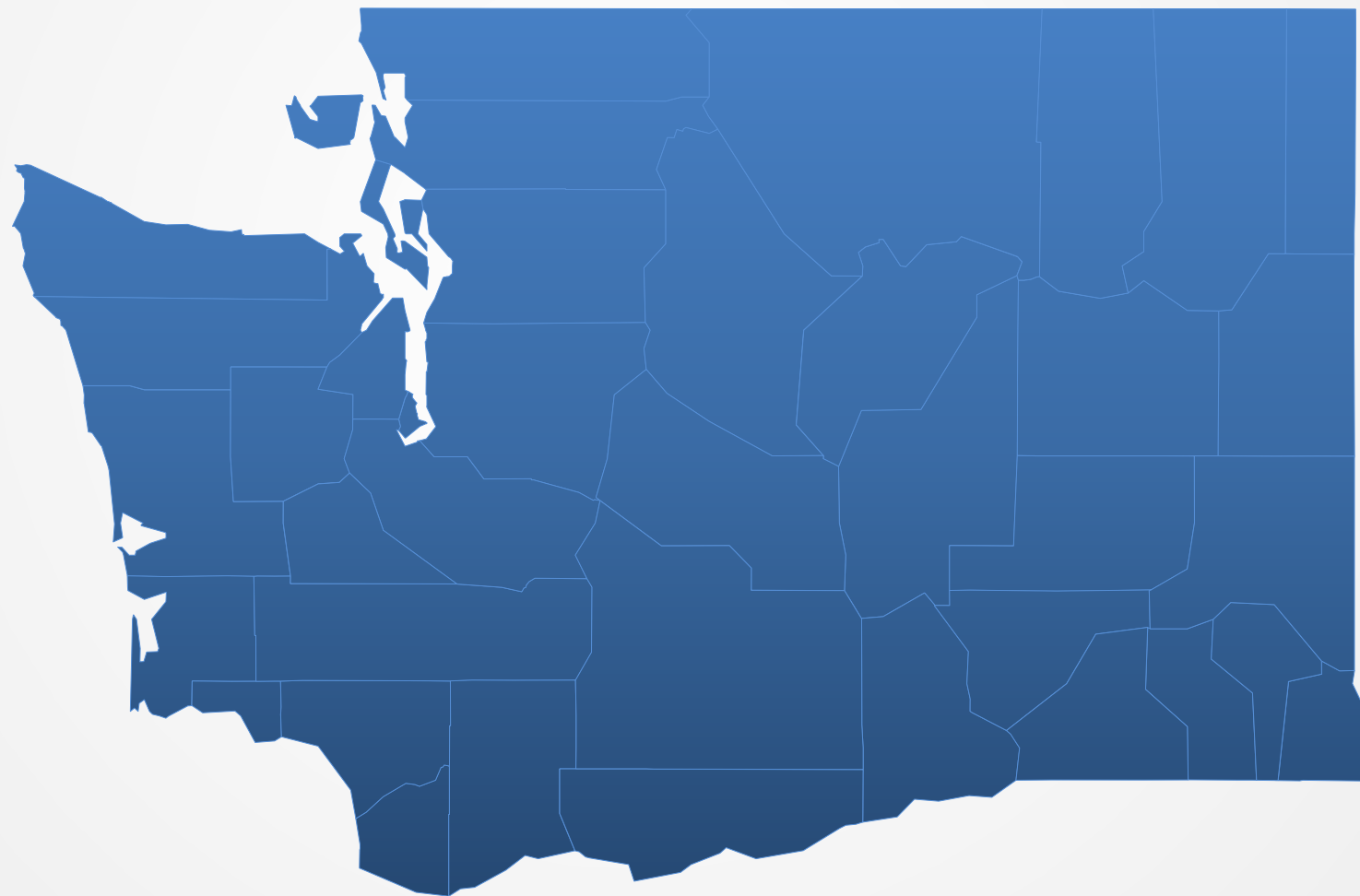


Traumatic Brain Injury Strategic Partnership Advisory Council

TRAUMATIC BRAIN INJURY

Strategic Partnership Advisory Council
of Washington State





Traumatic Brain Injury Strategic Partnership Advisory Council

Mission Statement (Art. II Bylaws)

The mission of the **TBI Council of Washington** is to advise and work in collaboration with the **Department of Social and Health Services (DSHS)** and other stakeholders to advise the **Governor**, the **Legislature** and the **Secretary of the Department of Social and Health Services** on the best ways to create and provide an array of coordinated, accessible services and supports which promote optimal quality of life for all individuals that have been impacted by a traumatic brain injury, including their families.



Traumatic Brain Injury Strategic Partnership Advisory Council

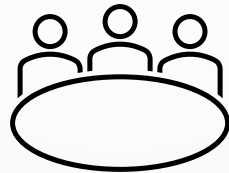
TBI Council Meeting Norms

- Respectfully engage and listen to discussions by allowing one member to speak at a time
- Address differences in opinion in a thoughtful and respectful manner
- Disclose any potential conflicts of interest that pertain to decisions made by the Council
- Adhere to meeting agenda timeframes and refrain from disrupting Council meetings
- Any accommodations for clarity or support among Council Members will be acknowledged and addressed
- Provide your Name, each time you are speaking
- Quorum - Over 50% of those assigned present



Traumatic Brain Injury Strategic Partnership Advisory Council

Approval of Meeting Minutes





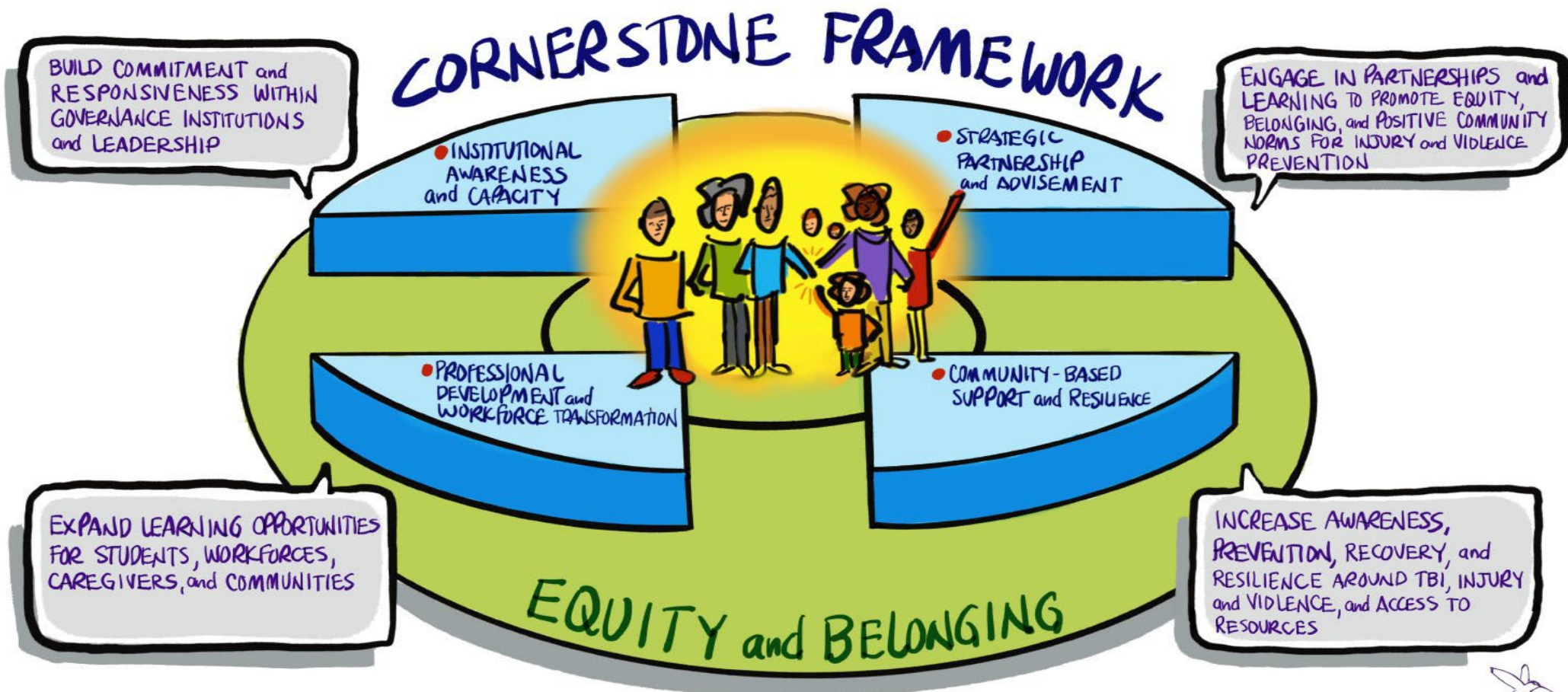
Traumatic Brain Injury Strategic Partnership Advisory Council

Council Member Recognition



Traumatic Brain Injury Strategic Partnership Advisory Council

Council Report





Traumatic Brain Injury Strategic Partnership Advisory Council

Cornerstones of Comprehensive Plan

Institutional Awareness and Capacity

Build commitment and responsiveness within governance institutions and leadership

Strategic Partnerships and Advisement

Engage in partnerships and learning to promote equity, belonging, and positive community norms for injury and violence prevention

Professional Development and Workforce Transformation

Expand learning opportunities for students, workforces, caregivers, and communities

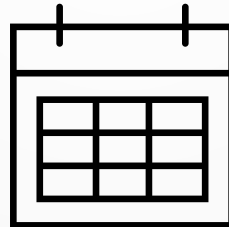
Community-Based Support and Resilience

Increase awareness, prevention, recovery, and resilience around TBI, injury and violence, and access to resources



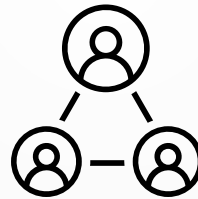
Traumatic Brain Injury Strategic Partnership Advisory Council

Comprehensive Plan Recap



Traumatic Brain Injury Strategic Partnership Advisory Council

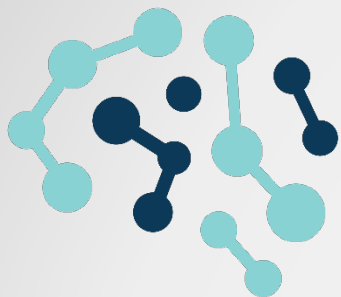
Re-elections



Traumatic Brain Injury Strategic Partnership Advisory Council



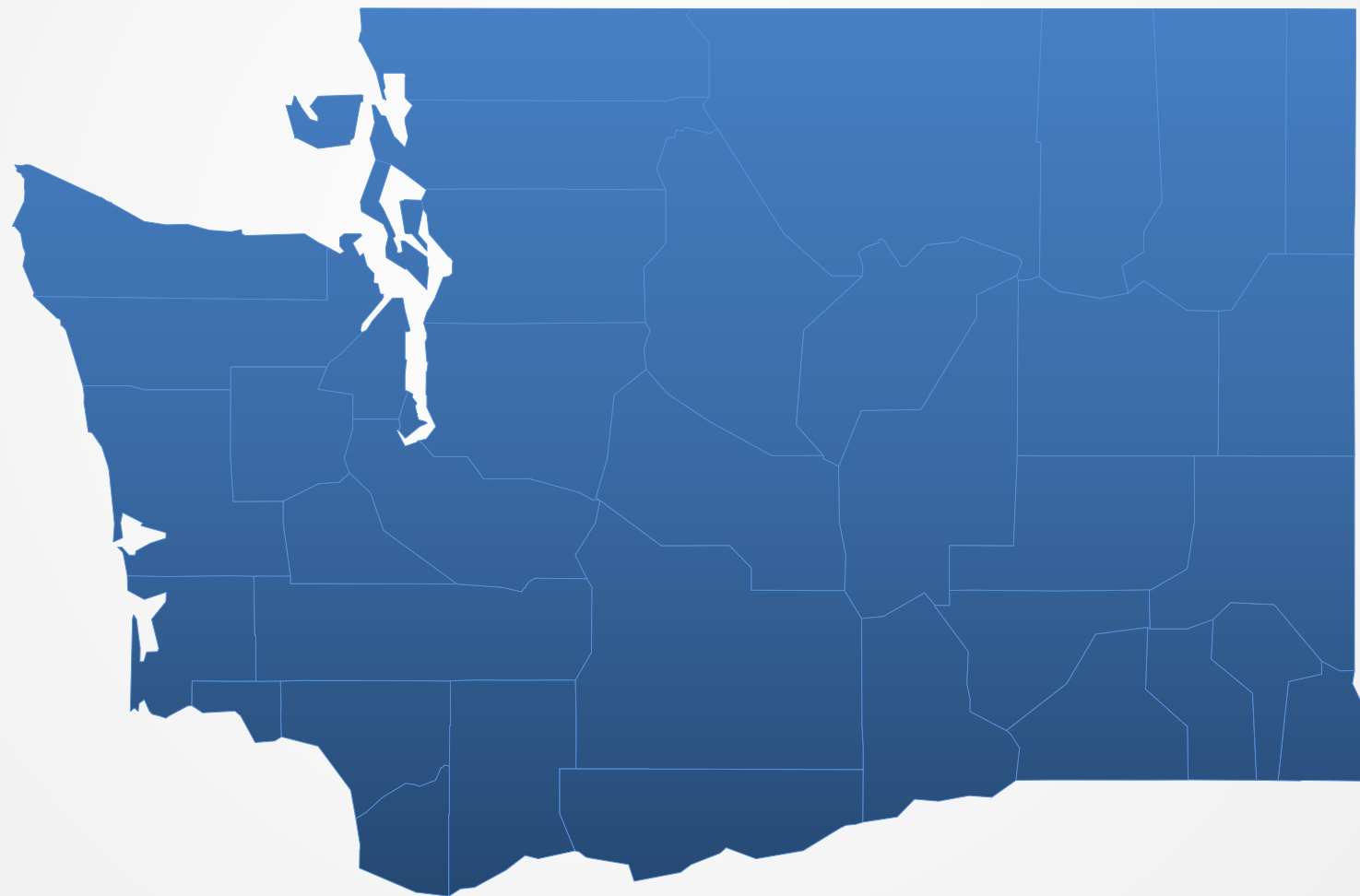
The Palouse



Traumatic Brain Injury Strategic Partnership Advisory Council

TRAUMATIC BRAIN INJURY

Strategic Partnership Advisory Council
of Washington State





2021-2023 TBI in Washington: Experiences and Trends with Services and Supports Survey

Summary Results



765 Participants Completed the Survey

- 437 People with Lived Experience of TBI
 - 7% of lived experience responses were reported by a family member, friend, or caregiver helping the person with TBI fill out the survey.
- 184 Caregivers
- 144 Service Providers

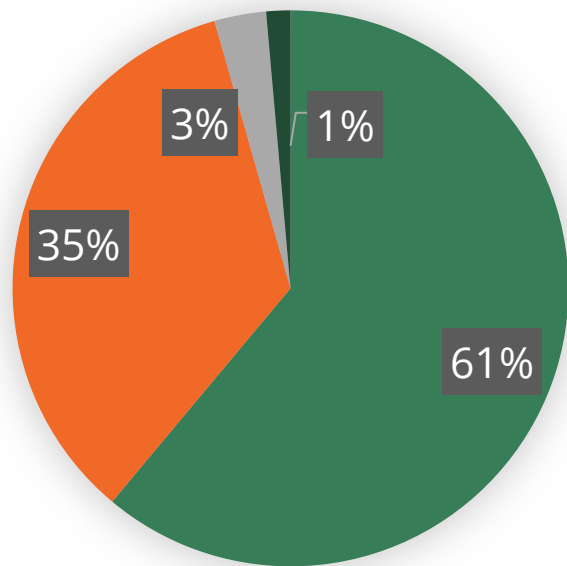


People with Lived Experience of TBI



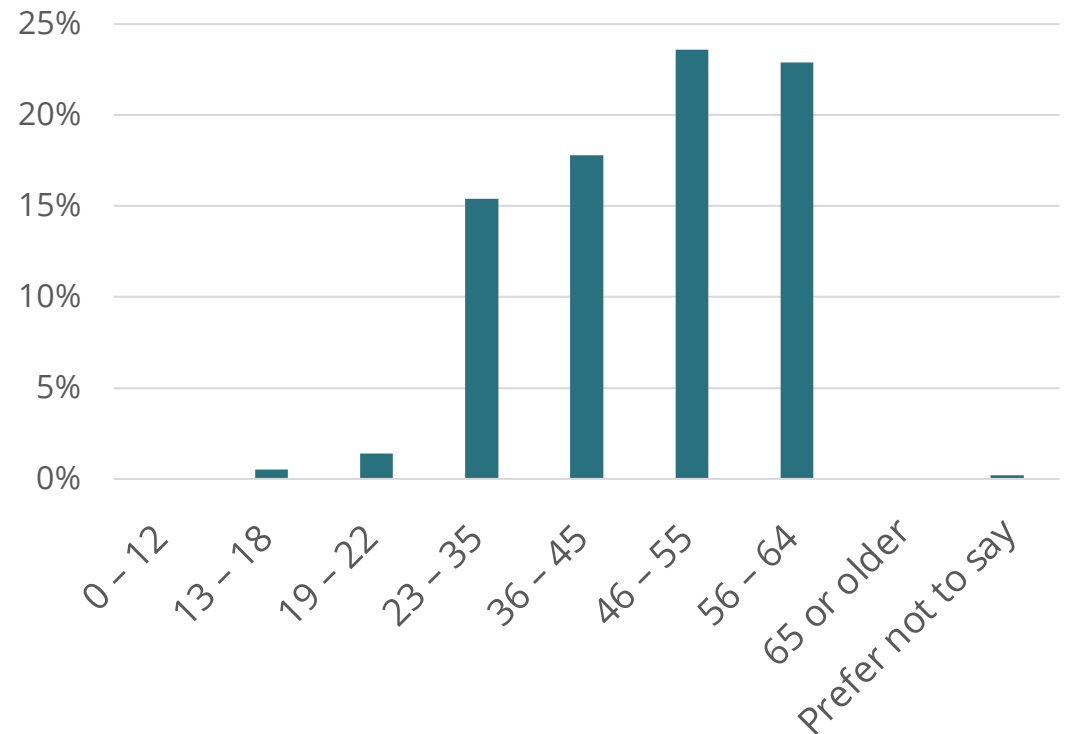
Lived Experience of TBI Demographics

How do you describe your gender?



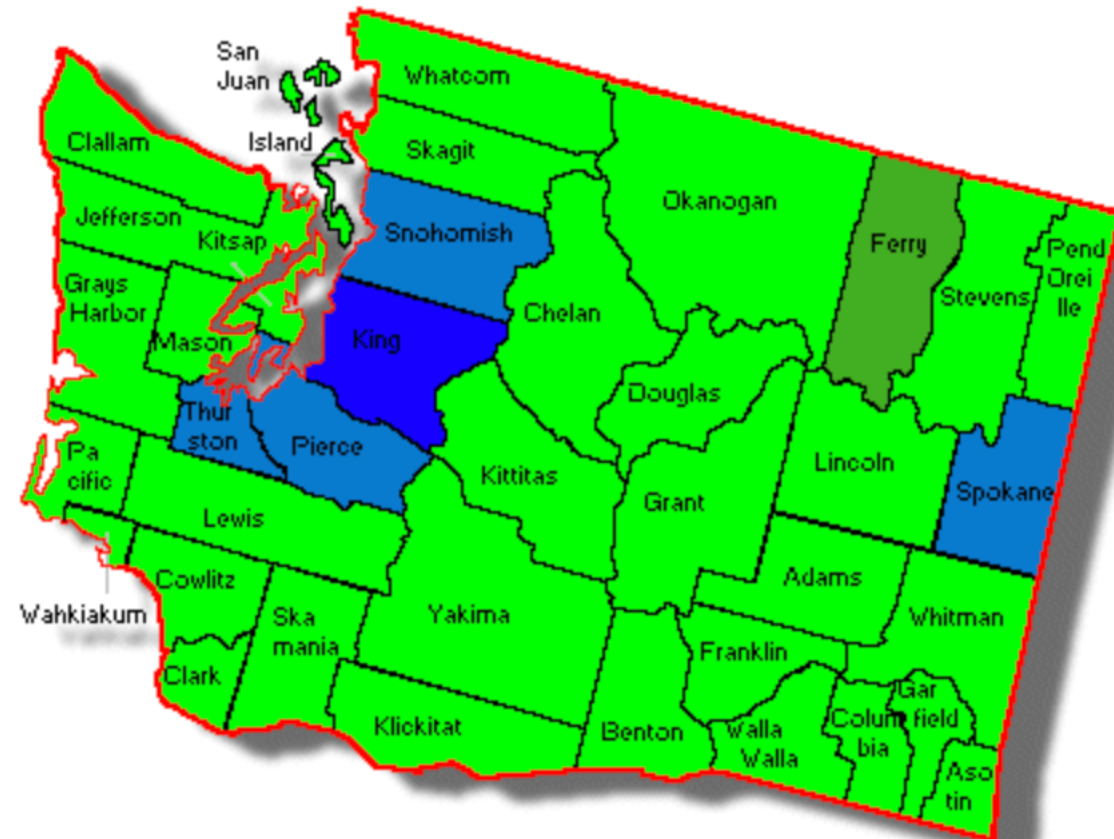
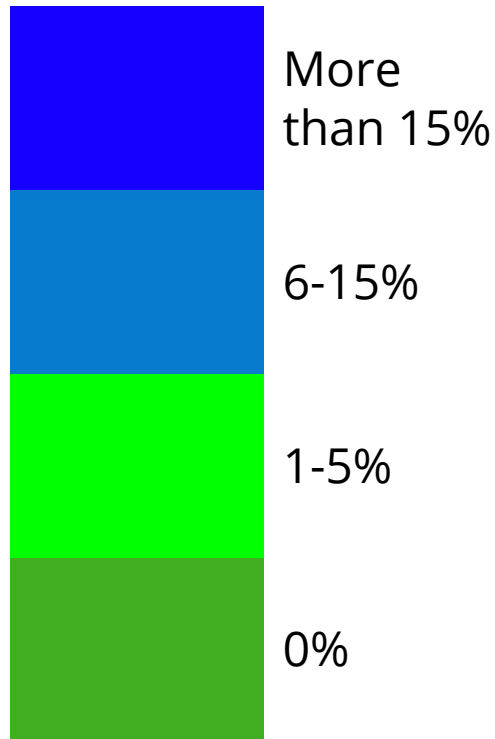
- Female
- Male
- Non-binary
- Prefer not to answer

How old are you?

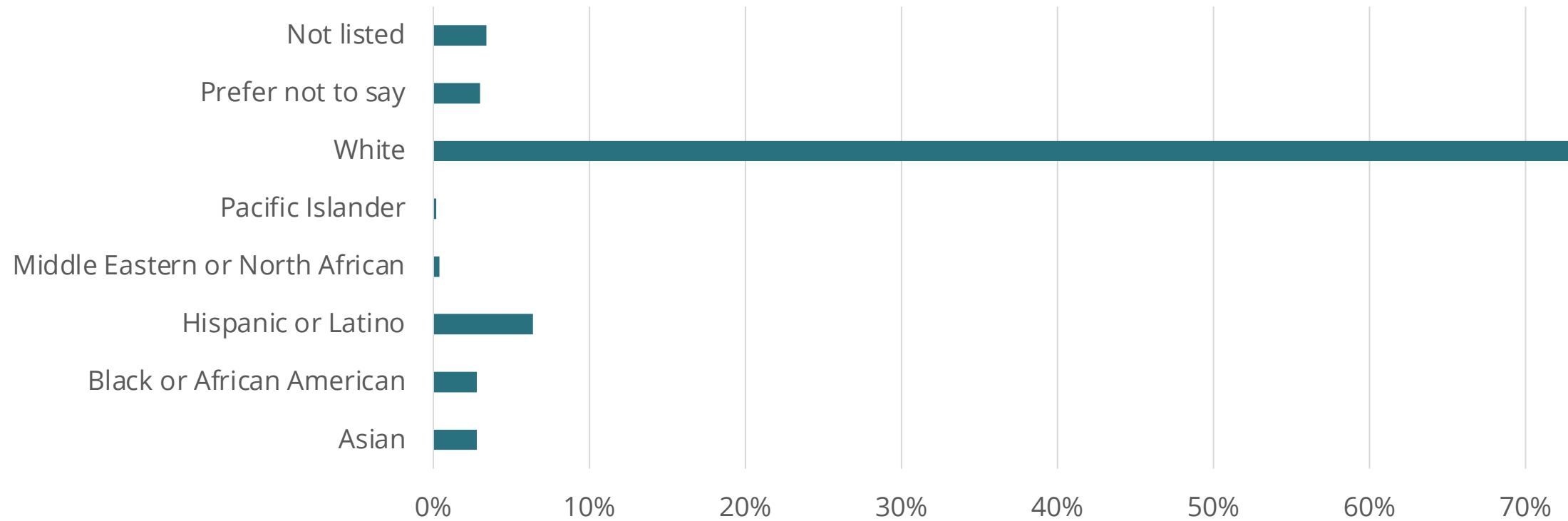


What county do you live in?

% of Participants



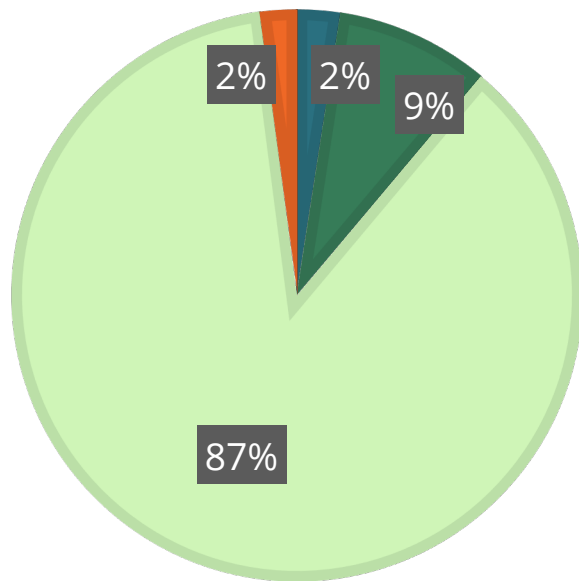
Which race / ethnicity describes you?



Veterans

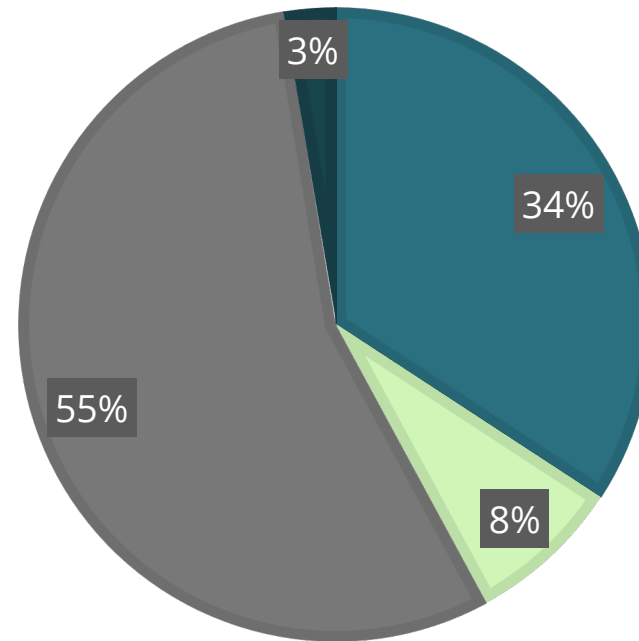
Have you served in the military?

■ Prefer not to say ■ Yes
■ No ■ Prefer not to say



Did your brain injury occur while you were active in the military?

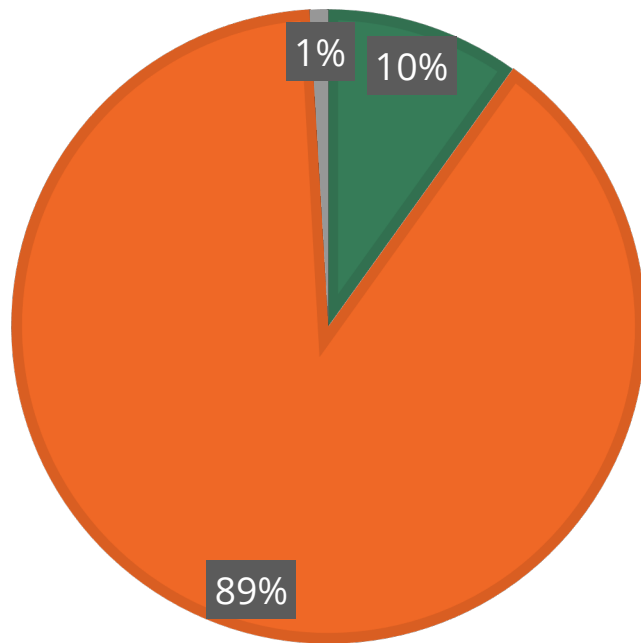
■ Yes ■ Maybe ■ No ■ Prefer not to say



First Responders

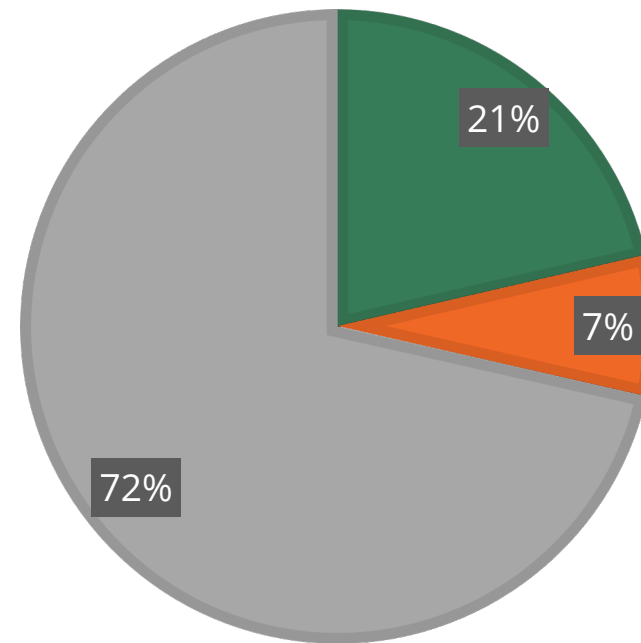
Have you served as a first responder?

■ Yes ■ No ■ Prefer not to say

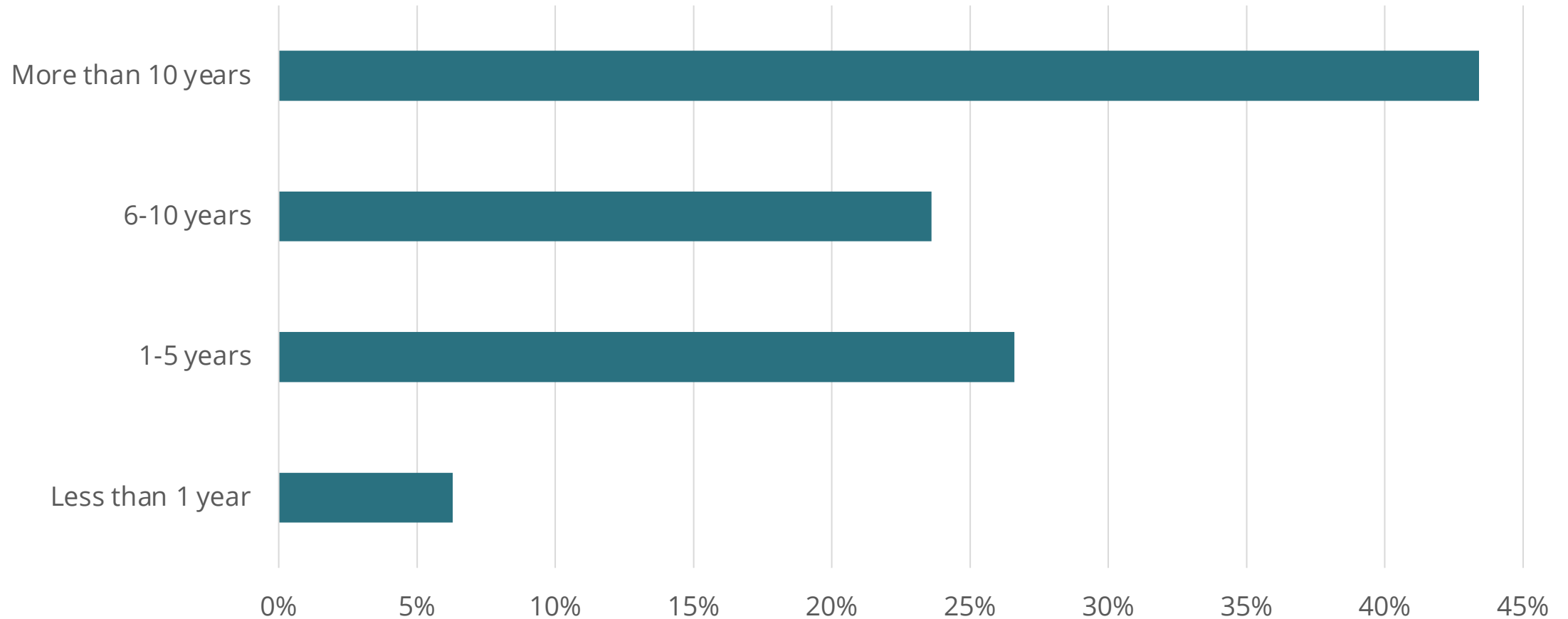


Did your brain injury occur in the line of your first responder duties?

■ Yes ■ Maybe ■ No



How long has it been since your injury?



At any point following your TBI, what has kept you from having your needs, related to your injury, met? (Click all that apply)	Percent (%)
I have not experienced difficulties getting my service needs met	17.9
Awareness	
I don't know what services I need	33.0
I don't understand the process to get services	27.7
I was not aware of the services	32.8
Availability	
I am on a waitlist or multiple waitlists	10.2
There aren't services located near where I live	18.1
Services are not available during the hours/ days I am available	6.0
Accommodation	
Difficulty finding providers who can communicate in my preferred language	1.1
Difficulty finding providers who understand my culture	4.3
Difficulty finding providers who are able to accommodate my communication needs	6.8
I have been turned away from providers due to my actions	4.7
Affordability	
I don't have health insurance	3.2
My health insurance doesn't cover the services I need	18.6
I can't afford the services I need	15.8
Acceptability	
Providers don't know how to help me	30.7
Providers don't believe my symptoms	20.3
I don't trust systems of service (e.g., law enforcement, social workers, health care workers)	11.7
Personal Resources	
I don't have access to stable housing	5.3
I don't have regular access to a telephone	1.7
I don't have regular access to technology / the Internet	5.1
I don't have access to reliable/ appropriate transportation	8.3
I live in an unsafe environment	4.5
I don't have the ability, skills, and/ or support I need to get services (e.g., schedule and keep appointments)	12.8
Other	12.6

At any point following your TBI, what has kept you from having your needs, related to your injury, met?

- Top 5 Choices:
 - I don't know what services I need (33%)
 - I was not aware of the services (33%)
 - Providers don't know how to help me (31%)
 - I don't understand the process to get services (28%)
 - Providers don't believe my symptoms (20%)

TBI and Awareness of Barriers

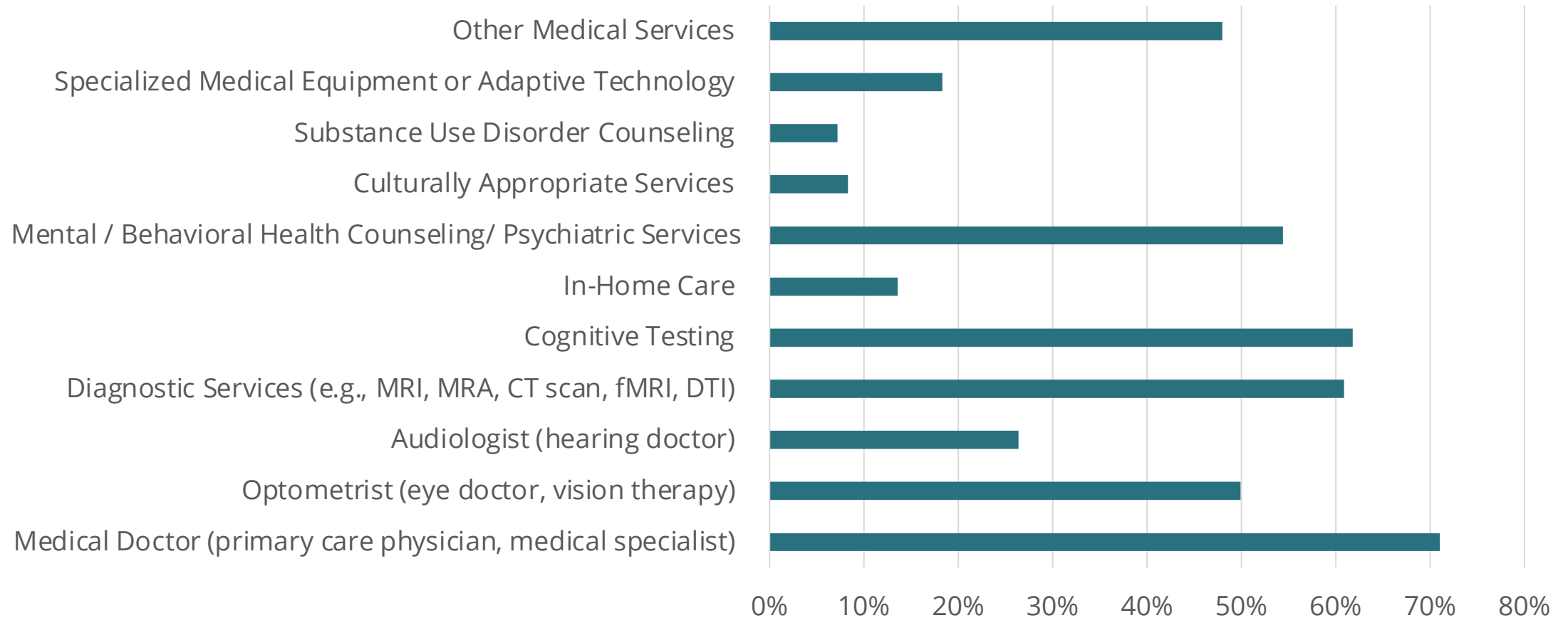
- There were 84 participants who initially indicated they had not experienced difficulties getting their service needs met.
- Of the 84, 26 (31%) provided data on at least one difficulty.
- They indicated 54 barriers- averaging over 2 barriers per participant that initially indicated they had not experienced difficulties.



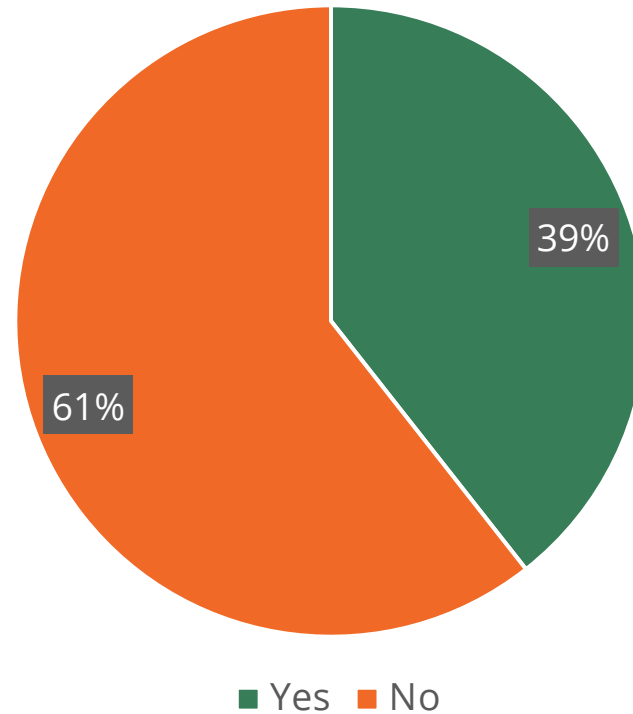
Medical Services



At any point after your injury, have you needed any of the following medical services?



Do you feel like your medical services needs were met following your TBI?

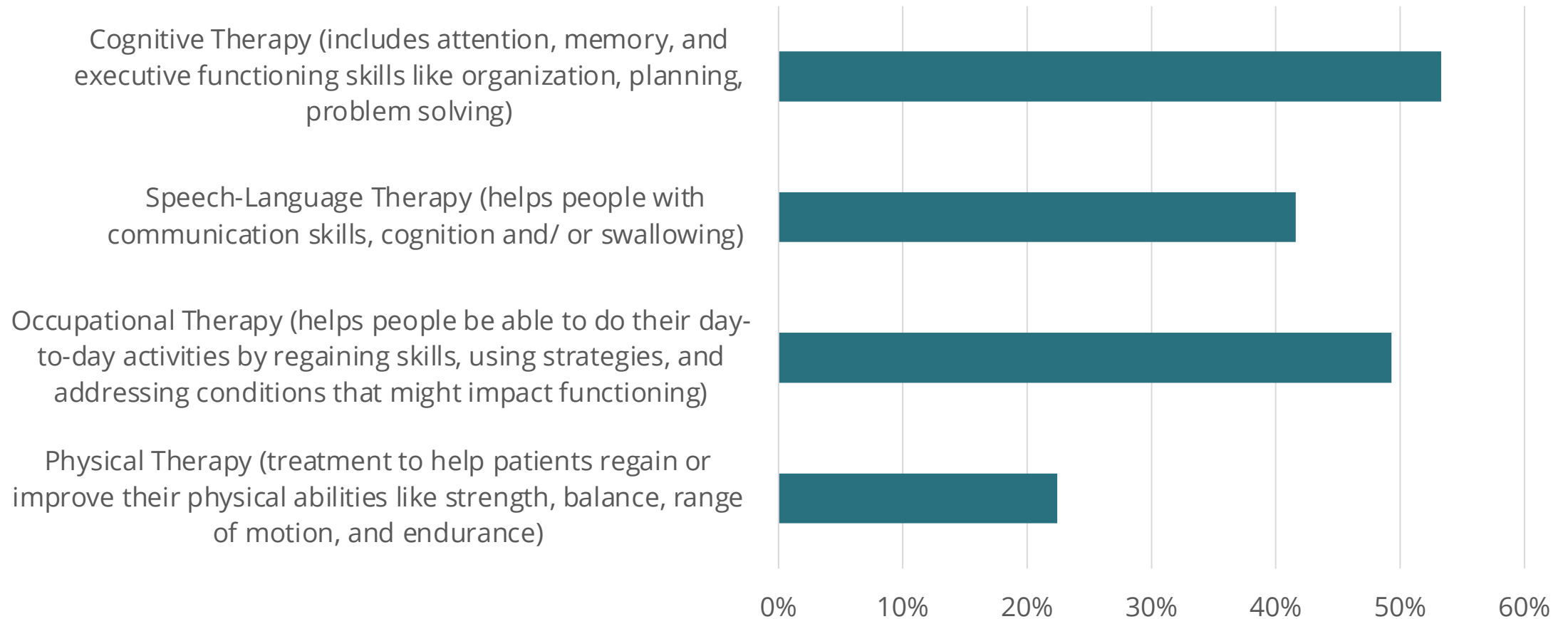




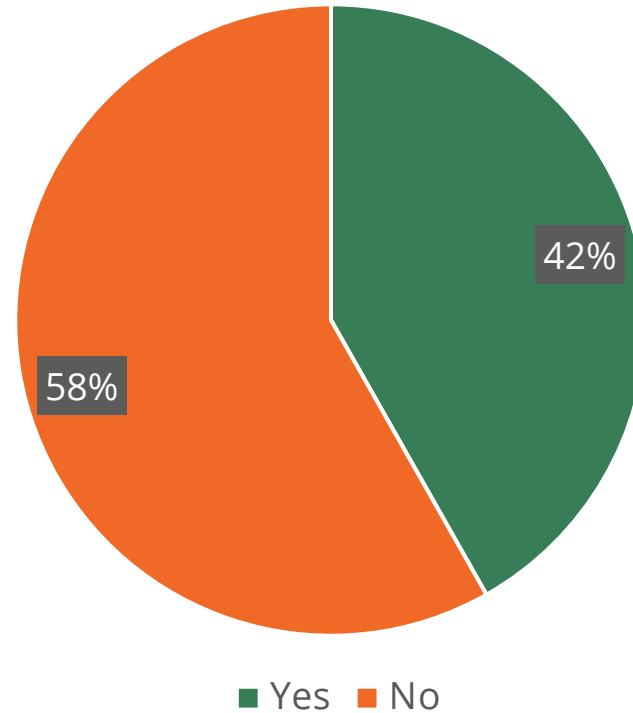
Rehabilitation Services



At any point after your injury, have you needed any of the following rehabilitation services?



Do you feel like your rehabilitation services needs were met following your TBI?

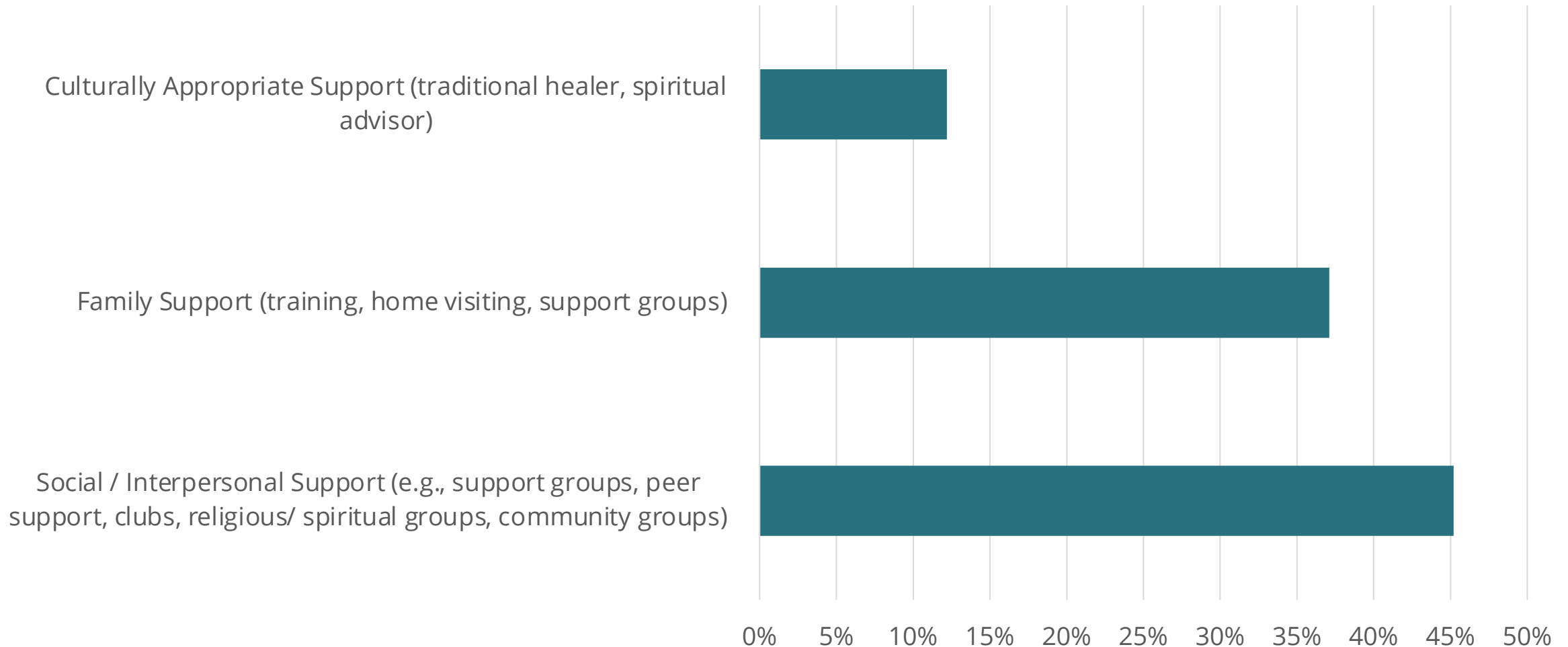




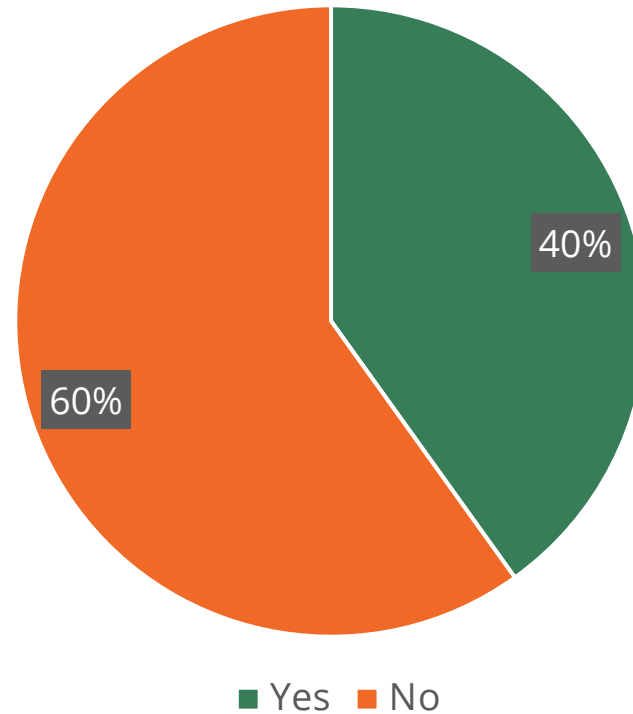
Social Support Services



At any point after your injury, have you needed any of the following social support services?



Do you feel like your social support services needs were met following your TBI?

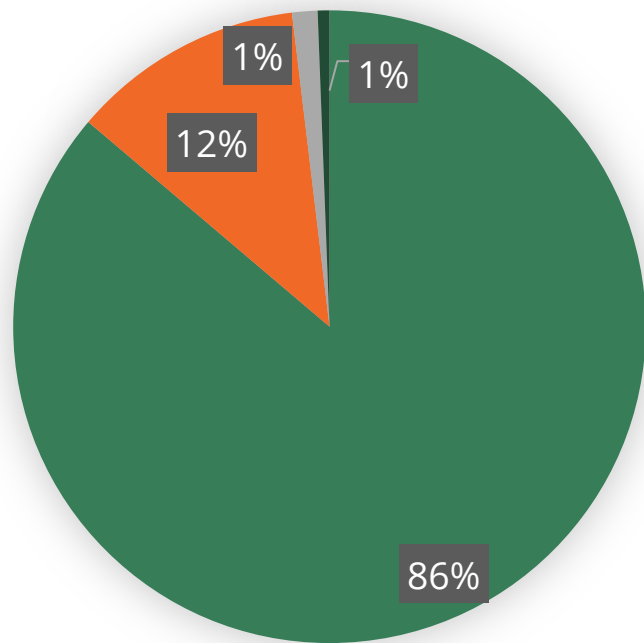




Caregivers

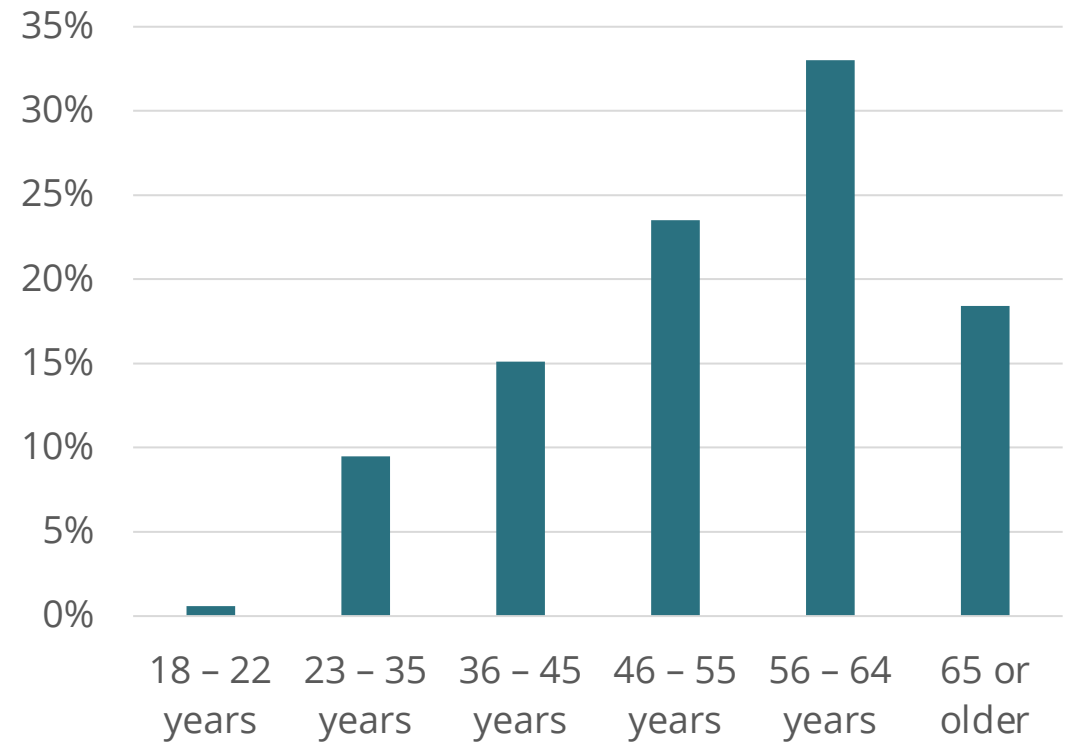


How do you describe your gender?



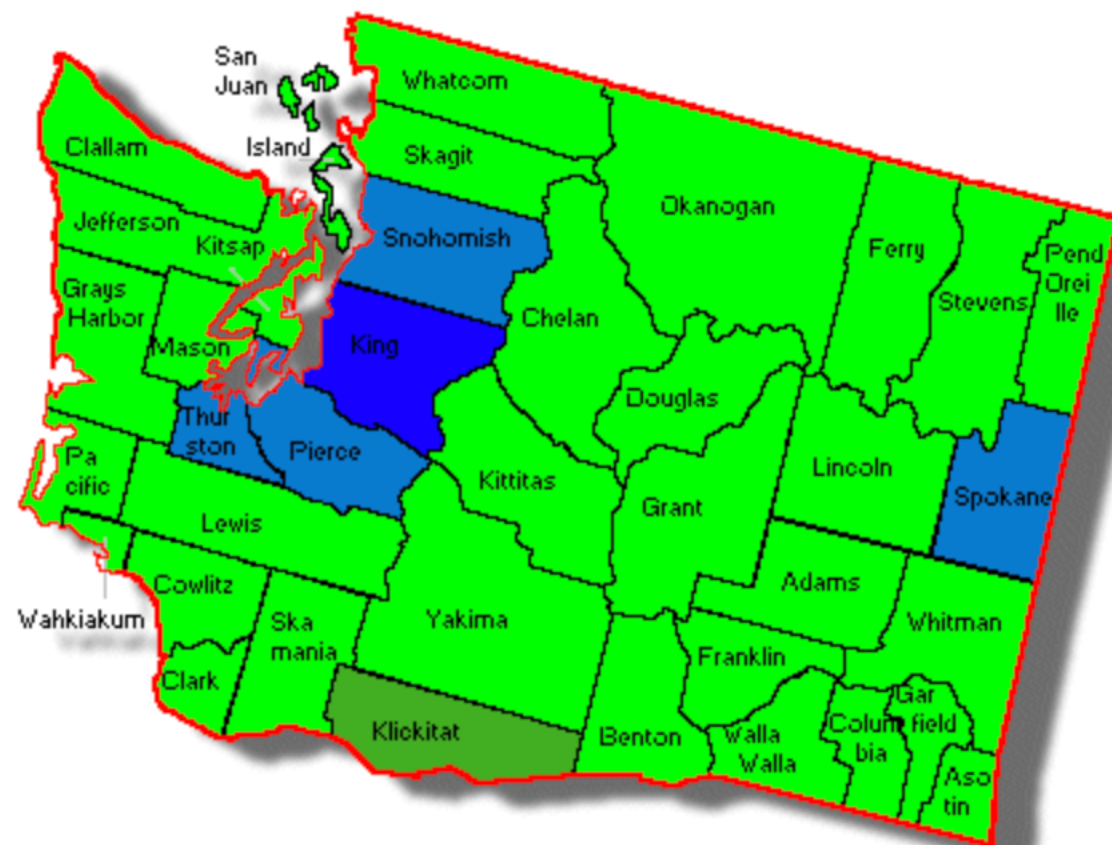
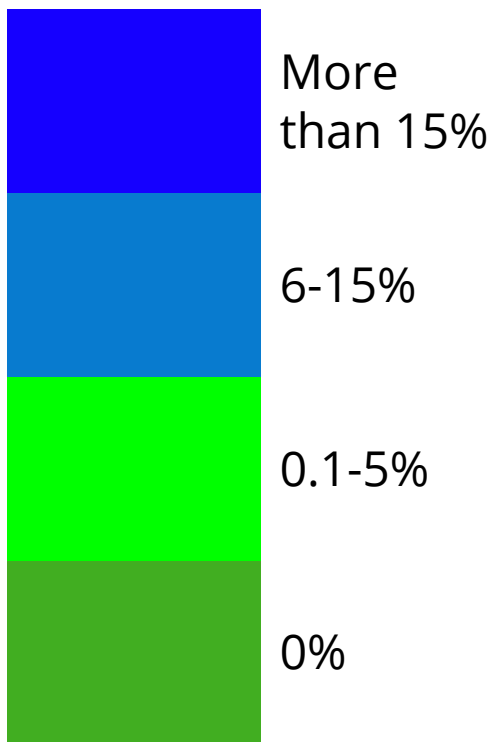
■ Female ■ Male ■ Non-binary ■ Prefer not to answer

How old are you?

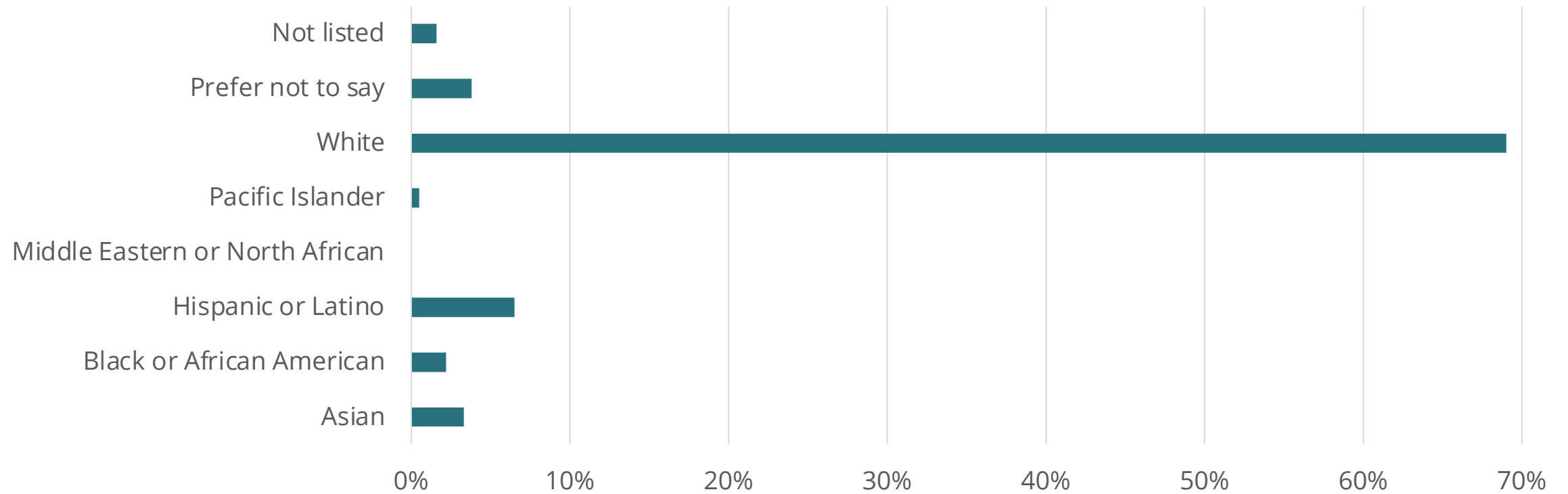


What county do you live in?

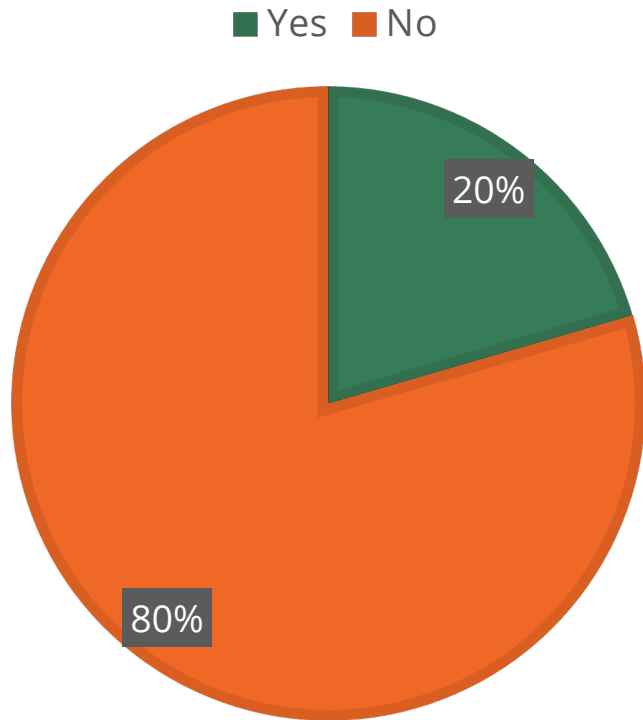
% of Participants



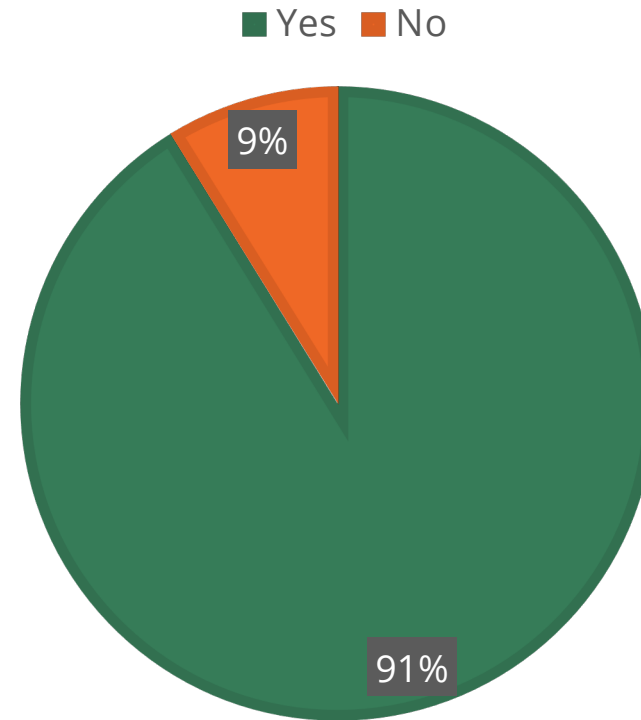
Which race / ethnicity describes you?



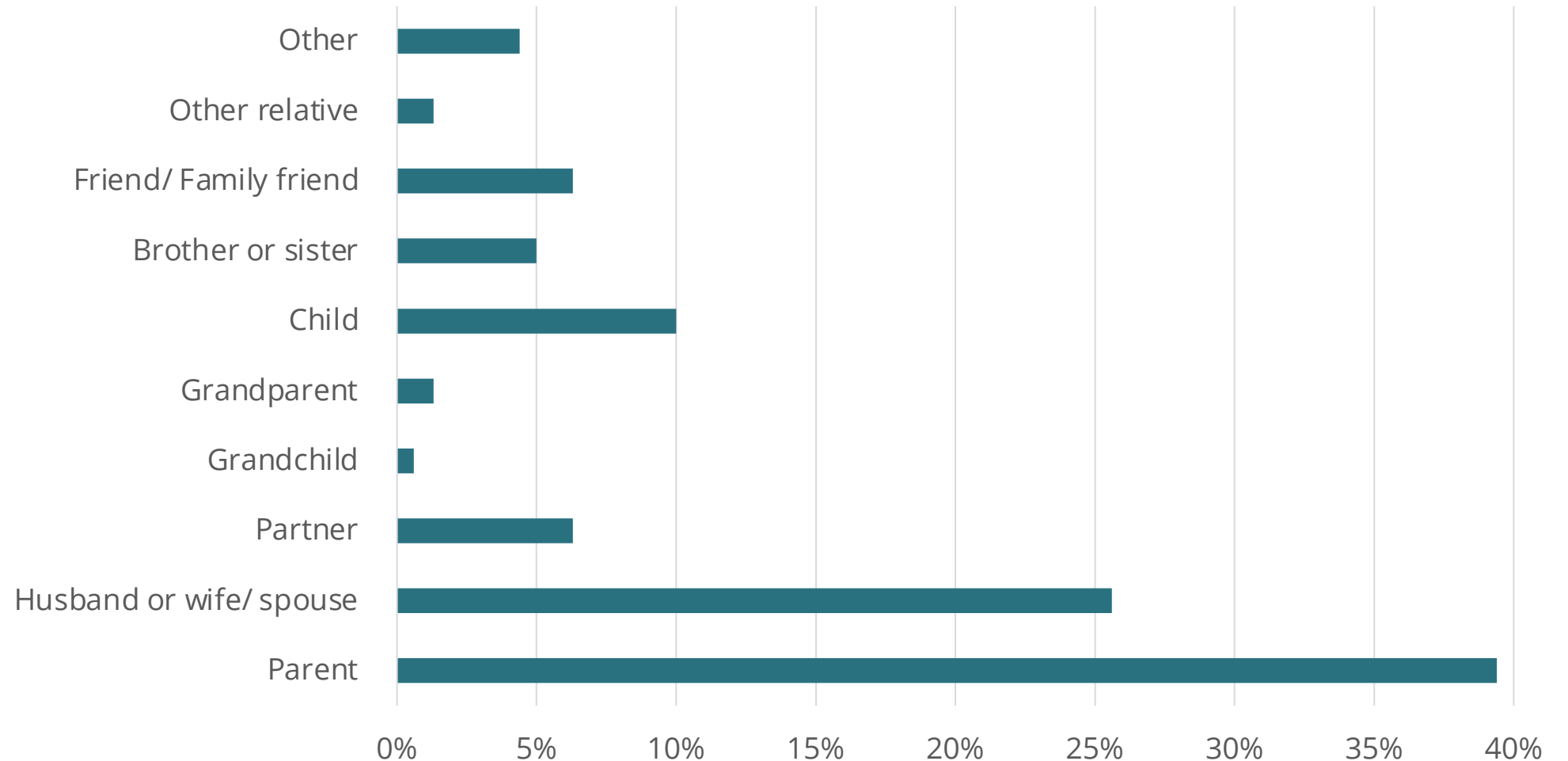
Do you identify as a person with a disability?



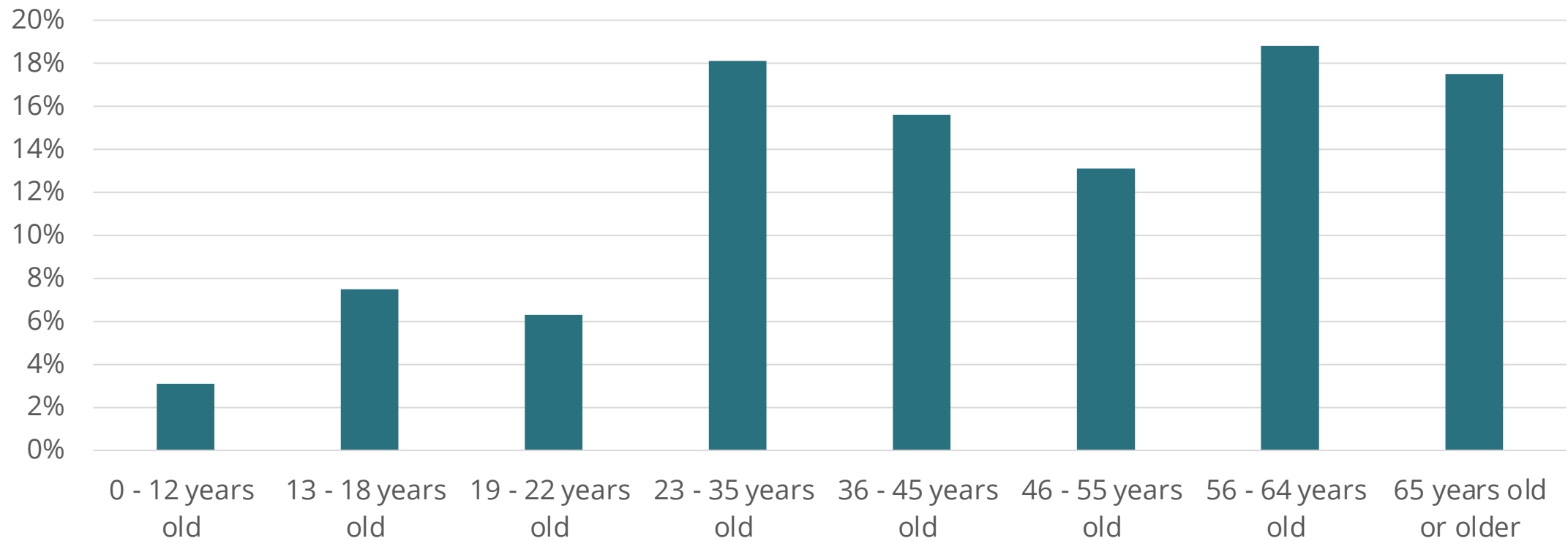
Do you provide unpaid assistance or care to a family member or friend because of a TBI?



What is your relationship to the person you care for?



What is the age of the person you care for?



What has made it difficult for you to access services for the person with a TBI for whom you provide care? (Click all that apply)	Percent (%)
I have not experienced difficulties getting my service needs met	11.4
Awareness	
Unaware of ways to get services needed	28.3
Difficulty in navigating through complex systems (e.g., health care, social services)	41.3
Availability	
Services needed not available nearby	28.3
Ineligible for services	17.4
Inability to take off from work to get to appointments/ fear of consequences at work for taking time off	12.0
Accommodation	
Difficulty finding a provider who understands TBI	33.7
Lack of peer support	16.8
Language barriers	0.0
Lack of cognitive accommodations in treatments	20.1
Lack of support to understand information and resources	24.5
Affordability	
Lack of insurance	3.8
Insurance doesn't cover the services needed	27.7
Inability to pay for services	14.7
Acceptability	
The person I care for is reluctant or refuses to participate in treatment	22.8
Frequent changes in service providers (having to start all over with someone new)	20.1
I don't trust systems of service (e.g., law enforcement, social workers, health care workers)	6.5
Inaccurate information received from provider	7.6
Difficulties in requesting medical documents needed	6.5
Providers don't believe the person with TBI's symptoms	10.3
Lack of communication with care team	12.5
Lack of coordination between care providers	28.8
Personal Resources	
Lack of transportation	10.9
Lack of regular access to a telephone	1.1
Lack of regular access to technology / the Internet	4.9
Lack of access to stable housing	5.4
Caregiver Challenges	
Caregiver's burnout (e.g., isolation, exhaustion, lack of sleep, loss of hope/ stamina)	42.9
Caregiver's physical health concerns	25.0
Caregiver's emotional distress or mental health concerns	33.7

What has made it difficult for you to access services for the person with a TBI for whom you provide care?

- Top 6 Choices:
 - Caregiver's burnout (e.g., isolation, exhaustion, lack of sleep, loss of hope/ stamina) (43%)
 - Difficulty in navigating through complex systems (e.g., health care, social services) (41%)
 - Difficulty finding a provider who understands TBI (34%)
 - Lack of coordination between care providers (29%)
 - Unaware of ways to get services needed (28%)
 - Services needed not available nearby (28%)

What aspects of caregiving have been challenging to you personally? (Click all that apply)

Percent (%)

Daily Living Aspects

Assisting with personal care such as eating, bathing, toileting, and dressing	17.9
Providing physical assistance, including lifting and carrying	15.8
Finding activities that they can participate in and are eligible to receive	40.2

Medical/Rehabilitation Aspects

Coordinating or providing transportation	22.3
Meeting the financial burden of caregiving	28.3
Coordinating and managing medications, medical equipment and other medical care, including care coordination	29.9
Understanding and managing their legal, financial and/or insurance issues or benefits	33.7
Feeling the need to "fight" for their care	43.5
Discrimination/ fear of discrimination by service providers	14.1

Social Aspects

Helping them to communicate with others	35.9
Educating others, including school and health care personnel, about their TBI	34.2
Managing and meeting their social needs	40.2
Changes in relationships with family and friends	45.7
Getting time with other family members, or meeting other family members' needs (14)	31.5
Loss of community	30.4

Emotional Aspects

Feelings of personal responsibility/ obligation to provide care (e.g., cultural, familial, religious)	42.4
Feeling trapped in my caregiving situation without alternatives	29.9
Feelings of anger	17.4
The feeling of walking on eggshells (tension because of unpredictability)	25.0
Managing difficult/ inappropriate behaviors	28.8
Managing changes in parenting	16.3
Managing violent/ aggressive behaviors	16.3
Managing and meeting their emotional needs	41.8
Managing the emotional or mental distress of caregiving	34.2
Taking care of myself	40.8
Processing grief and loss	32.6
Lack of hope, losing hope overtime	21.2

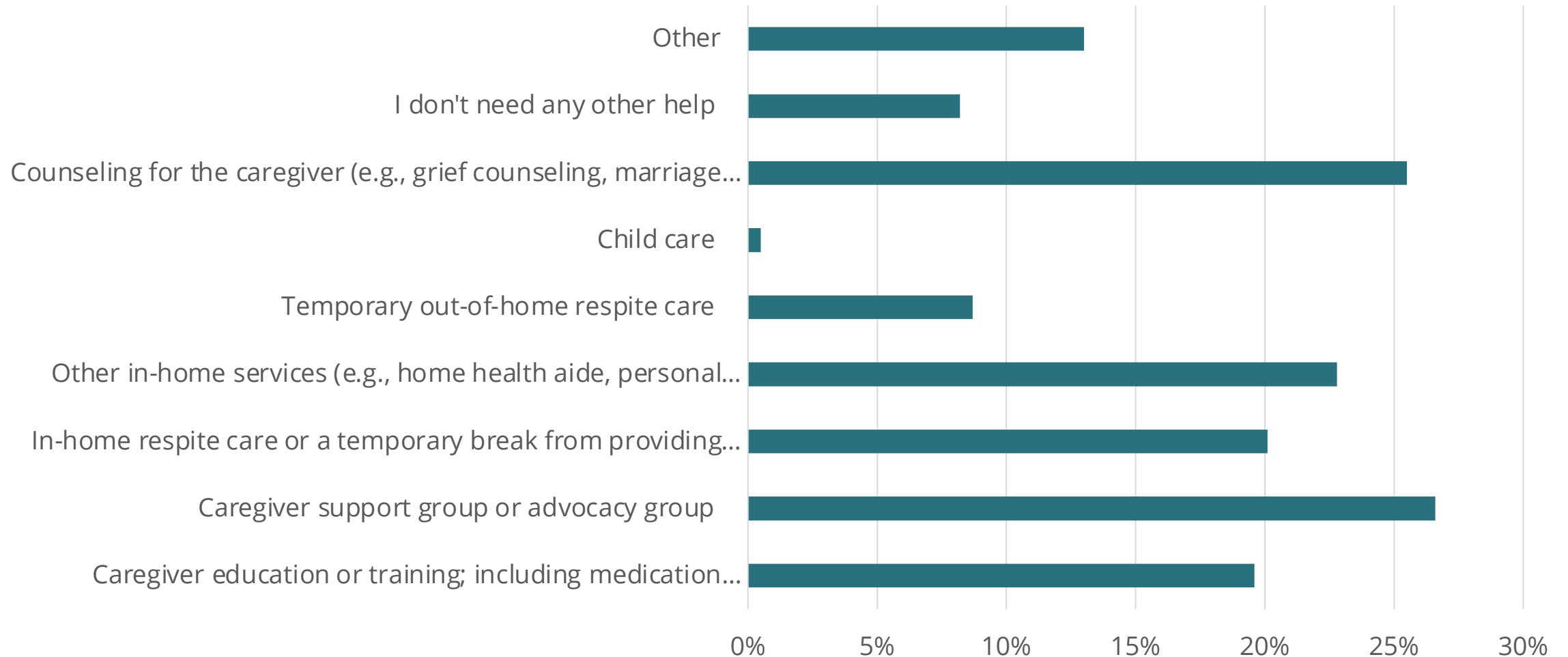
Respite Care

Getting a short break from caregiving	21.2
Finding paid help such as personal care attendants or respite workers	14.1
Finding a temporary substitute to provide occasional care for them	19.6

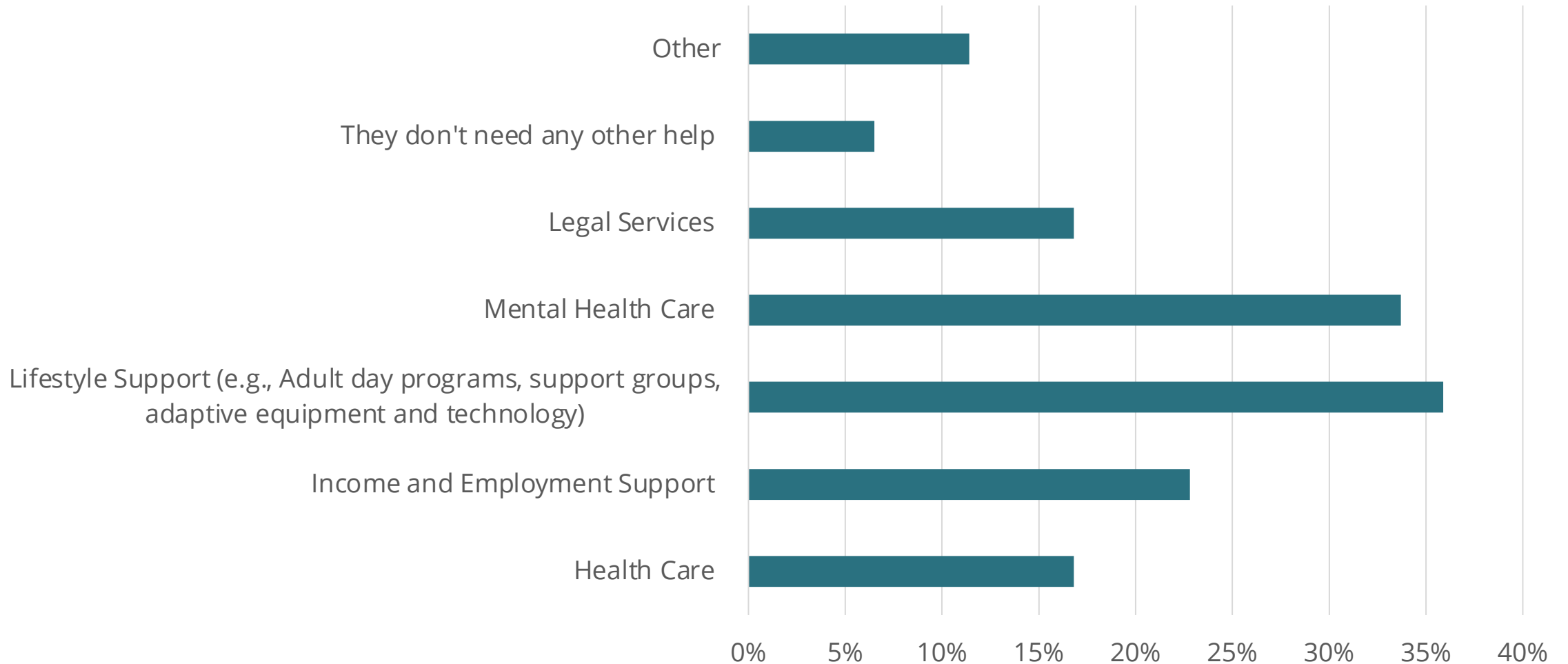
What aspects of caregiving have been challenging to you personally?

- Top 7 Choices:
 - Changes in relationships with family and friends (46%)
 - Feeling the need to "fight" for their care (43%)
 - Feelings of personal responsibility/ obligation to provide care (e.g., cultural, familial, religious) (42%)
 - Managing and meeting their emotional needs (42%)
 - Taking care of myself (41%)
 - Finding activities that they can participate in and are eligible to receive (40%)
 - Managing and meeting their social needs (40%)

What caregiving-related services would help you as a caregiver?



What programs or services would help the person you care for?

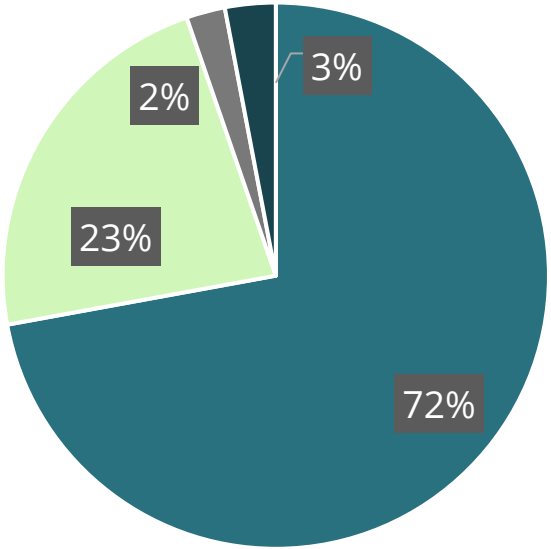




Service Providers

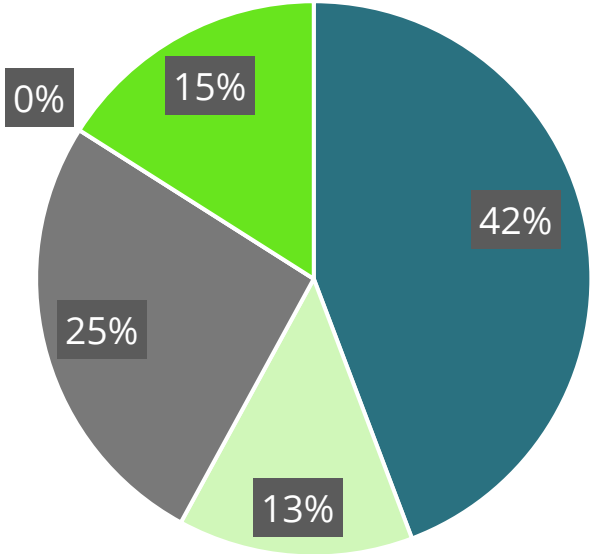


How do you describe your gender?



■ Female ■ Male ■ Non-binary ■ Prefer not to answer

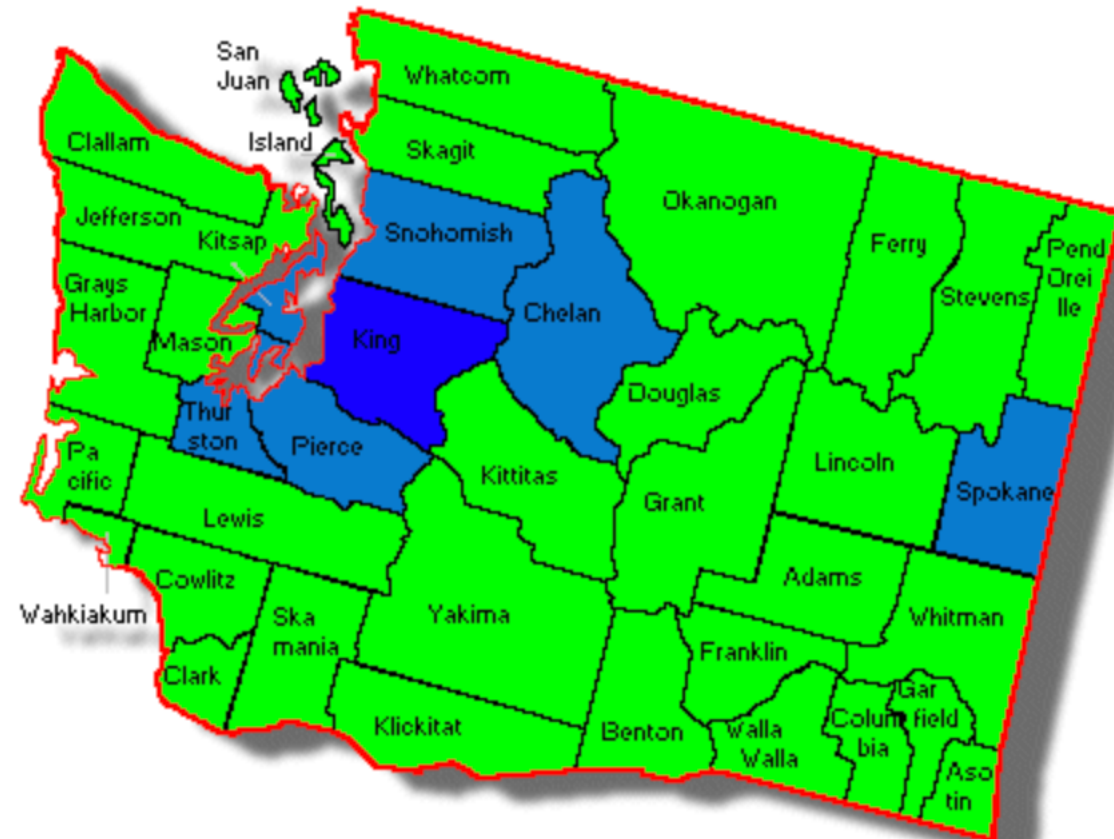
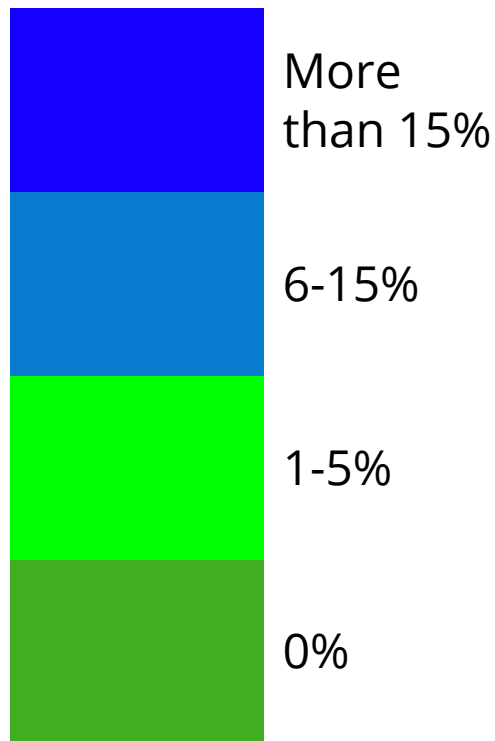
Which of the following best describes the community where you work or provide services in?



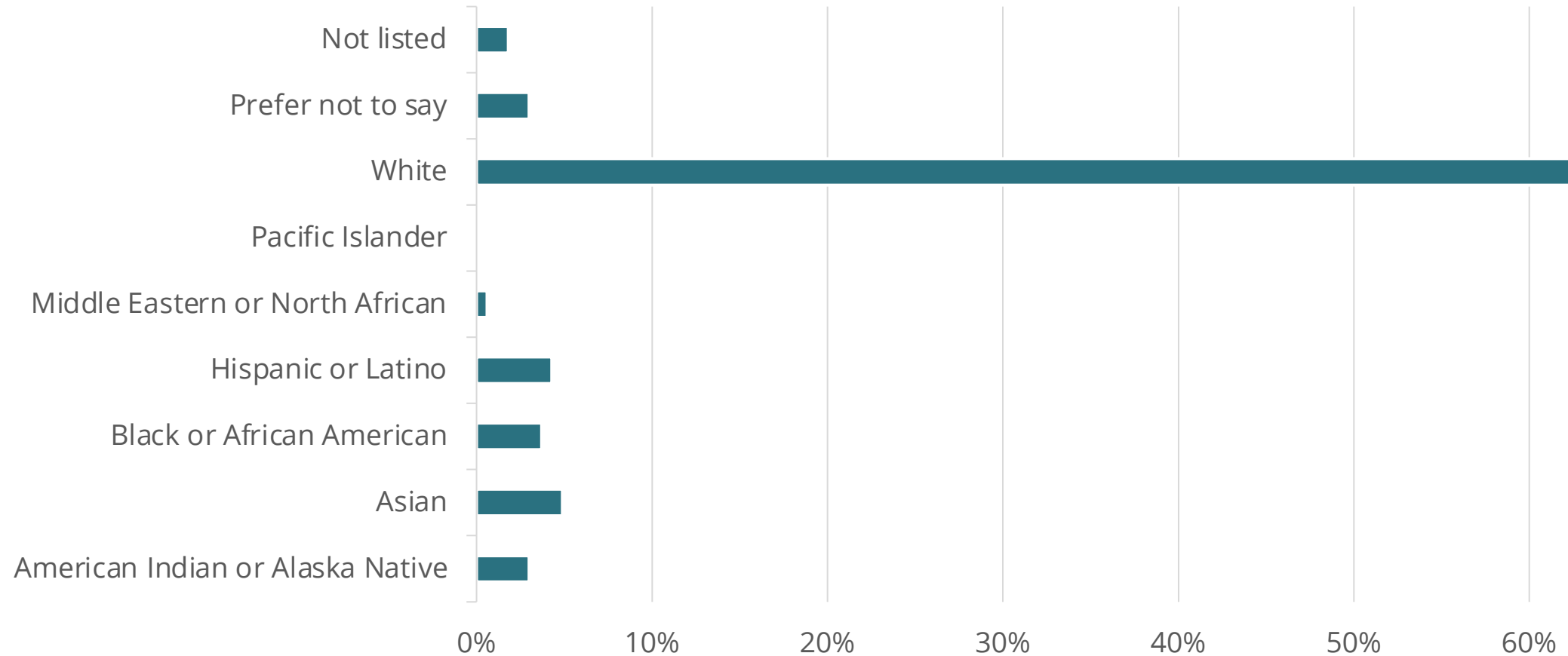
■ City or Urban community
■ Suburban community
■ Rural community
■ Tribal
■ Other

What county or counties do you work or provide services in?

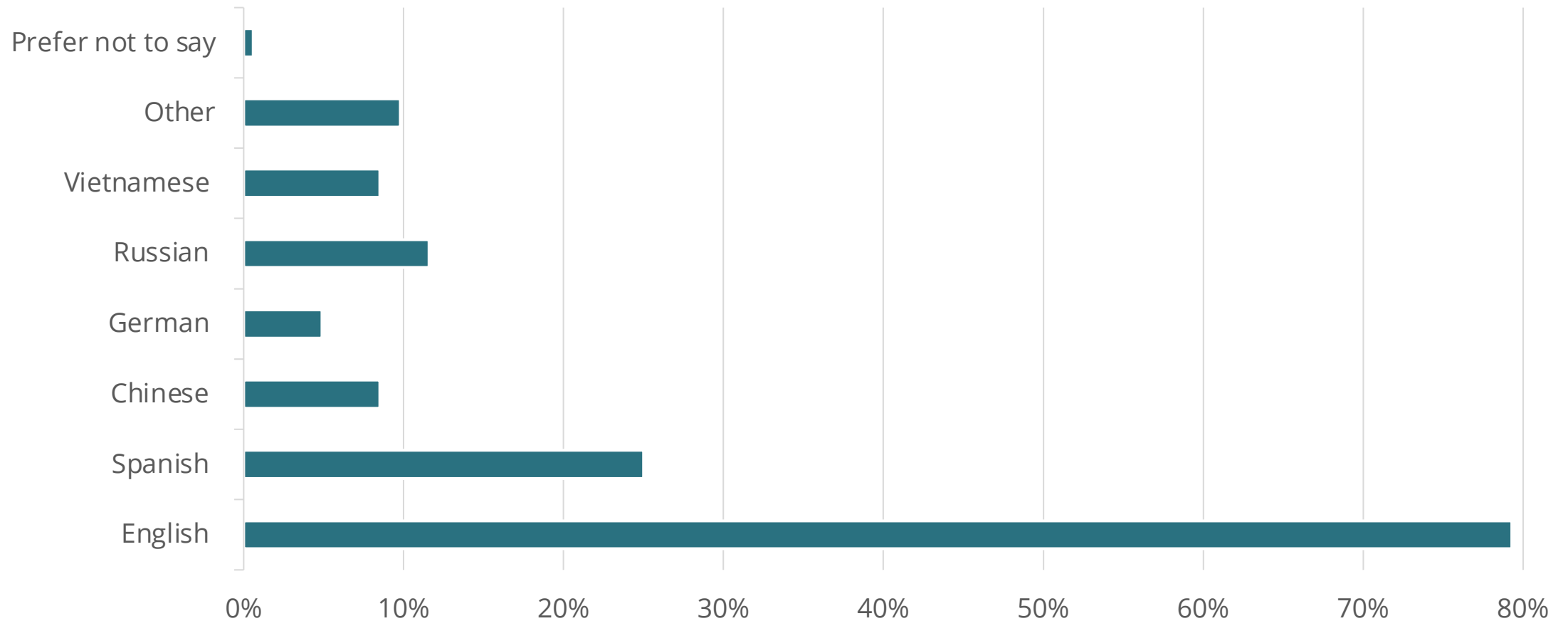
% of Participants



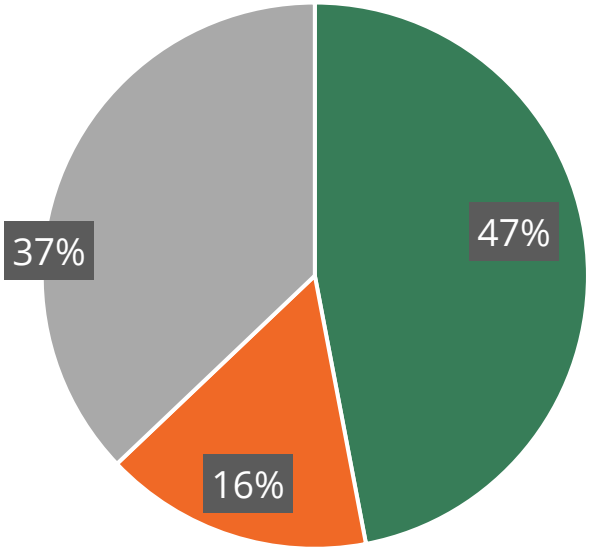
Which race / ethnicity describes you?



What language(s) are used to provide services at your organization?

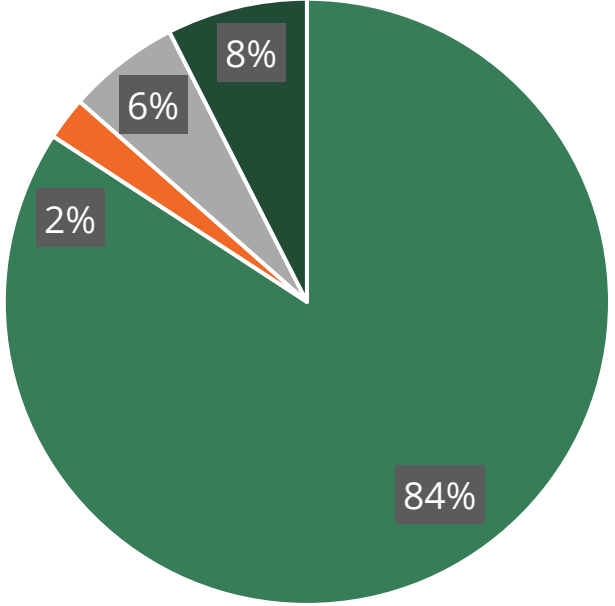


Does your organization accept Medicaid?



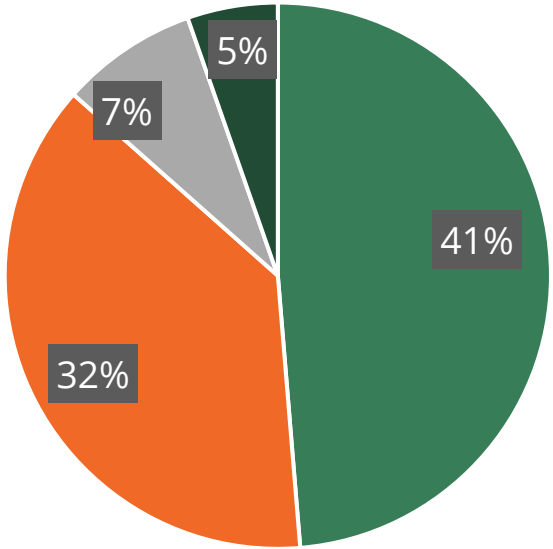
■ Yes ■ No ■ Not applicable

Do you currently serve clients with TBI?



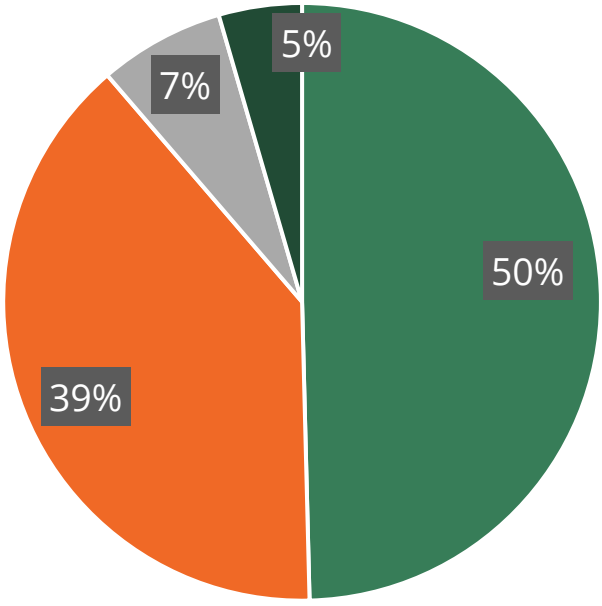
■ Yes
■ No
■ Not applicable
■ I don't know

Does your organization screen for TBI?



■ Yes ■ No ■ Not applicable ■ I don't know

How would you rate your confidence serving clients with TBI?



■ Confident
■ Neutral
■ Not confident
■ Not applicable

What has made it difficult for you to provide services to clients with TBI? (Click all that apply) Percent (%)

What has made it difficult for you to provide services to clients with TBI? (Click all that apply)		Percent (%)
Awareness		
Unaware if clients have TBI		16.5
Symptoms of TBI overlap significantly with other health conditions, which can make identification difficult		42.1
Time since TBI (Gap between injury and diagnosis/ care)		18.3
Lack of TBI specific assessment tools		18.3
Availability		
Issues with hiring, recruiting and/or high staff turnover		13.4
Inadequate TBI training and expertise in the workforce		28.0
Unaware of best practices for serving clients with TBI		18.9
High caseloads		17.7
Interventions are limited and don't have accommodations for those with TBI		15.9
Not enough transition support options when a client returns to the community		23.2
Insufficient number or density of facilities		12.2
Services are too far from client's home		19.5
Limited referral network of providers that have experience working with clients with TBI		29.9
Licensing or regulatory restrictions on capacity to serve this population		0.6
Accommodation		
Concerns about workers compensation/ litigation when working with clients with TBI		9.8
Challenges accessing medical records or documenting a credible history of TBI		12.2
Co-occurring behavioral health concerns (e.g., depression, anxiety, suicidal tendencies)		39.0
Affordability		
Low reimbursement rates/ inadequate or no funding		18.3
TBI is not a covered diagnosis in my organization		9.8
Difficulties with client maintaining treatment compliance		18.3
Difficulties with client's challenging or inappropriate behaviors		20.7
Client's lack of trust in providers or treatment		14.6
Client's loss of hope (they don't believe anything will help)		15.9
Provider discouragement/ lack of confidence in systems		9.1
Client's reluctance to participate in treatment		12.8
Treatments are not approved, have limited approval, or are experimental		5.5
Inability to meet the needs of clients with more complex needs		18.3
Staying connected with clients over time to serve the chronic / long term impacts of TBI (28)		12.2
Systems not built to support and serve clients with TBI		29.9
Challenges in care coordination and navigating siloed systems of care (e.g., health, mental health, vocational rehabilitation)		28.7
Personal Resources		
Level of caregiver/ family support		23.2
Lack of support resources when a person needs an elevated level of care beyond our organization's capabilities		34.8
Clients have transportation issues		25.6

What has made it difficult for you to provide services to clients with TBI?

- Top 5 Choices:
 - Symptoms of TBI overlap significantly with other health conditions, which can make identification difficult (42%)
 - Co-occurring behavioral health concerns (e.g., depression, anxiety, suicidal tendencies) (39%)
 - Lack of support resources when a person needs an elevated level of care beyond our organization's capabilities (35%)
 - Limited referral network of providers that have experience working with clients with TBI (30%)
 - Systems not built to support and serve clients with TBI (30%)



Qualitative Analysis

Long answer responses and interviews



Interviews

- In total, 19 people who took the survey were interviewed. 9 people with lived experience of TBI, 6 caregivers, and 4 service providers.
- Interview participants were chosen based on two factors.
 - The first factor was demographics. Participants from traditionally marginalized communities (e.g., non-white, living in rural areas, lower socioeconomic status) were a priority for interviews. We also selected participants with military or first responder service.
 - The second factor was the participants' responses to the survey. Participants who had unique responses and responses that were representative of the data set were chosen for interviews.



Findings



Lived Experience of TBI

1. Caregiver relationship is essential. A loss of this relationship can be catastrophic
2. Compassion and patience are important to recovery
3. It is difficult to know what services are available and who is eligible
4. Providers often don't listen to or believe lived experience
5. Providers are often unsure how to serve people with TBI

Caregivers

1. Caregivers are not prioritized by anyone, leaving their needs unaddressed
2. TBI Caregivers face long term, intense challenges
3. People with lived experience of TBI need support with awareness and acceptance of injury
4. People with lived experience of TBI have difficulty obtaining diagnosis and treatment
5. TBI support groups provide needed community

Service Providers

1. Advocacy is needed to support persons with TBI
2. Insurance companies refuse coverage of services needed post TBI
3. Providers are unsure how to serve people with TBI and their families
4. Need for TBI training and resources for all stakeholders
5. Partnerships/relationships between professionals and organizations are helpful



Recommendations





Invest in Connections

1. Host regional provider network meetings and workshops
2. Offer TBI provider trainings
3. Host regional and community specific virtual TBI support groups with regular in person events

Make the Invisible Visible

1. Develop a strategy for screening for lifetime history of TBI; including when to screen, who screens, and action plans for positive TBI screens
2. Increase the communication of information about current programs for people with TBI and caregivers to communities
3. Invest in education, awareness, and advocacy campaigns about TBI

Support the Supports

1. Meaningfully include the perspective of caregivers in all TBI initiatives, recognizing the critical roles of in-home/family caregivers and their unique needs.
2. Advocate for development of caregiver supports (e.g., respite care, mental health care, financial compensation, targeted education).
3. Support group facilitators should be knowledgeable and paid for their time.

Limitations

Populations not well represented in this data set are:

- those living in long term care facilities
- current K-12 students
- those living on tribal lands

It is recommended that further resources are invested to continue relationship building with these communities and work towards identifying their specific needs.

Questions?

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