2017

Annual Needs Assessment Report

Brain Injury Alliance
IOWA

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Objectives and Methodology

Objectives

The purpose of this study is to understand the needs of those with a brain injury, or their families/providers, and where needs are falling short

Specific objectives include:

- What are the top needs of those with a brain injury
- What they want key stakeholders to understand about a brain injury
- Barriers to receiving services

Methodology

116 online conversations (including both quantitative metrics and a qualitative conversation)

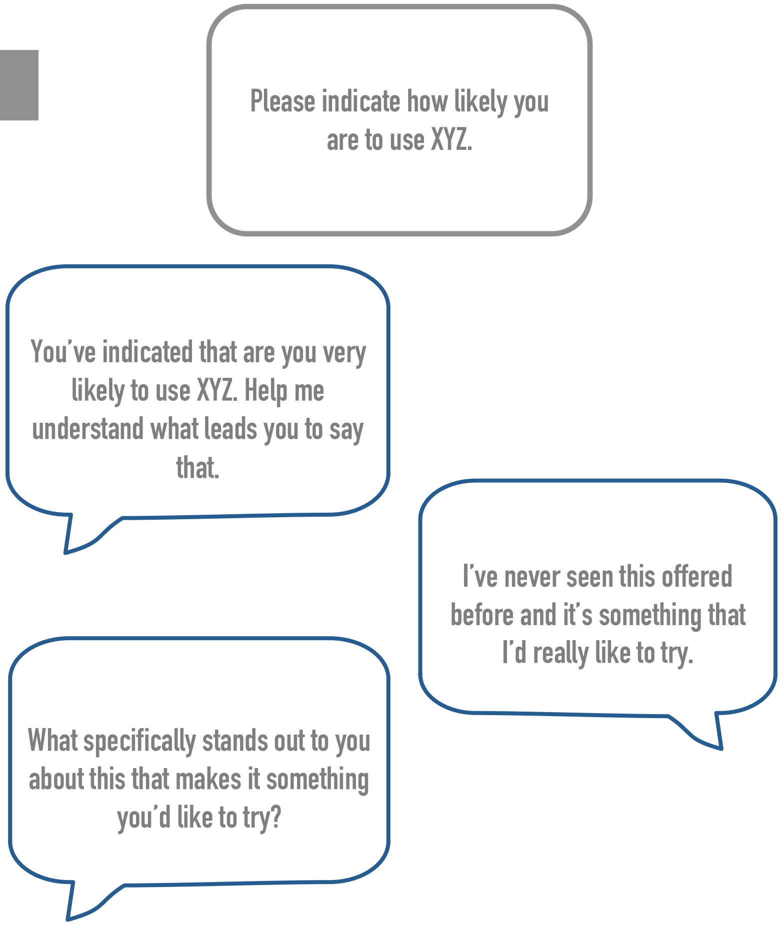
All respondents had some connection to brain injuries and services

Achieved 32 completes from those with a brain injury, 29 from family members of those with a brain injury, 42 from professionals providing either direct or indirect care, and 13 from "Other" relationship

Quester Methodology

Quester specializes in one-on-one online conversations that involve both **close-ended** and **open-ended** questioning. These conversations are conducted by the industry's only software-based moderator, backed by artificial intelligence.

Conversations are analyzed by trained linguists and statisticians who help guide decisions with data and context. Hearing from hundreds or thousands of people at a time, qualitative research moves beyond anecdotes and into evidence.



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Key Findings

The mission of the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research, and support.

Founded in 1980, the Brain Injury Alliance of Iowa (BIAIA) is the second charter chapter of the Brain Injury Association, Inc. Our members include people with brain injuries, their family members, their friends, and professionals who work with people who have had brain and head injuries.

We exist to support, assist, and advocate for persons with acquired brain injury and for their families. We advocate for and with people with brain injury and family members by responding to their challenges and representing their concerns through legislative efforts and active support of programs created for their needs.

We serve the brain injury community by working to secure and develop community-based services, encouraging research, establishing support groups, and providing access to pertinent information and resources.

We educate the public and increase statewide awareness of brain injury as a serious disability with lifelong consequences through the development and distribution of informational materials, news, and notices of conferences, symposia, and other meetings.

We strive to prevent brain injury through public awareness, education, and legislation. For more information, e-mail us at info@biaia.org or call us at 1-855-444-6443

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Key Takeaways

It's already difficult dealing with symptoms of a brain injury on a daily basis knowing you'll never be the same, but it becomes even more difficult when health providers or case managers aren't educated enough on brain injury or assume you are being lazy or rude just because you can't remember. Providers need to be patient and understand that they are trying … but this is hard!

Also, please understand that no two injuries are the same. Don't put someone into a "brain injury box" and assume they'll be just like every other brain injury patient. Providers need to fully understand them and their needs on an individual level. That might require more custom care, or more time spent with them, because each injury is different.

> *"Sometimes with brain injury we honestly, unfortunately, forget. We are not trying to be rude or non-compliant. We just have lost our ability to have a memory. So please remain patient with us. We absolutely need supportive help and knowledgeable brain injury providers in our lives. Each injury affects every person differently."*

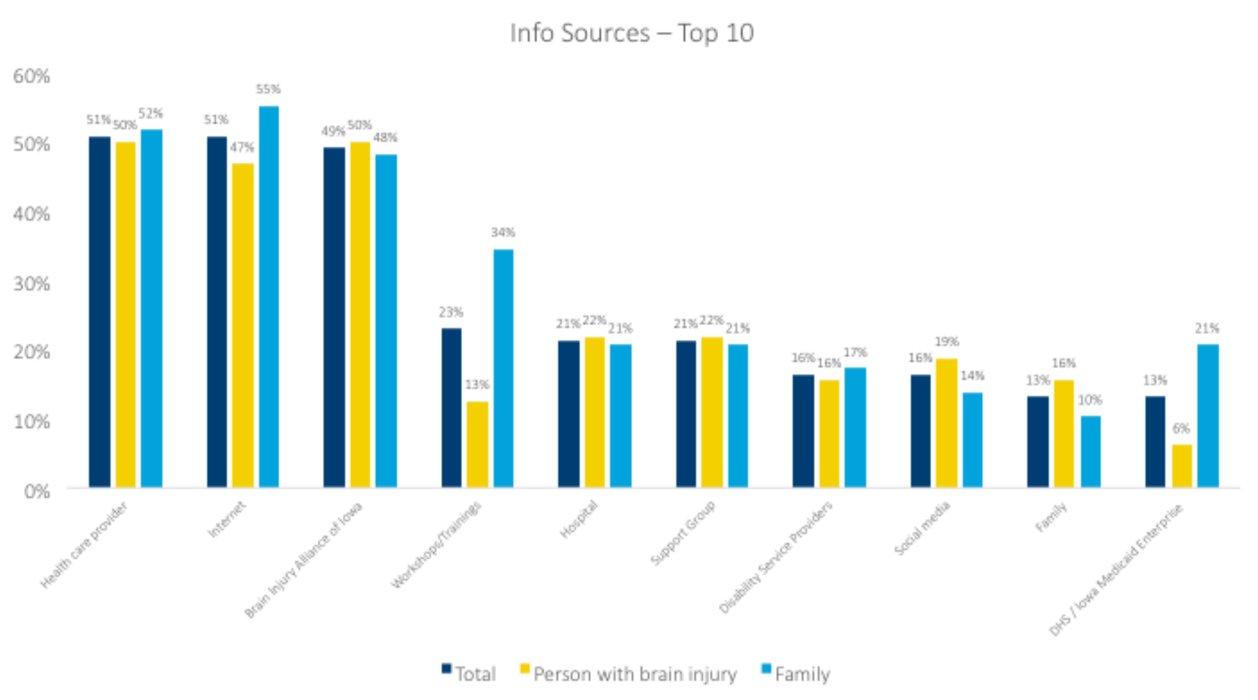
> *"Put yourself in the shoes of a TBI patient's mom or dad, put your son or daughter in the shoes of the patient. Do you want your child to wait for certain medical treatments or wait for two years on the brain injury waiver waiting list for assistance getting him or her home? How would you cope with being 200 miles from your injured child? Stop thinking like law makers, start thinking like humans."*

The most requested changes are more waiver slots and increased funding for services. Wait times are too long to get approved and monthly caps or denied services add to frustrations.

Funding should be increased, but with an emphasis on *qualified* providers who can actually help. Dealing with poor providers doesn't help those with brain injury – if you don't educate providers, an increase in funding is just throwing money at the problem.

The plea to those in charge or policy makers is largely emotional. Hear us. Understand me. This could happen to anyone – don't wait until it happens to a loved one. Start caring now … start thinking like humans.

Q2: First, where do you get most of your health information?



The most popular sources of info for those with a brain injury and family are a health care provider, internet, and the Brain Injury Alliance of Iowa

The community needs to understand the impact of a brain injury is often invisible; with the right support, people with brain injuries can thrive

Q5: Now I would like you to think about your community, the world around you. Your community may not fully understand brain injury. Thinking about all your experiences, talk to me about what you would like the members of your community to better understand about brain injury.

You can't see brain injury: They may not look disabled on the outside, but they often struggle on the inside; It takes longer to do things like write a check in a checkout line or fill out a form; Patience and understanding are needed

They are not dumb: They may have challenges in some areas but excel in others; They were once "just like you" but now have difficulties sorting things out

They are not lazy: They may look normal on the outside, but they face mental challenges that impact their abilities to work, work efficiently, or even perform simple tasks on their own

They can be successful with the right support: Want communities to understand people with brain injuries can thrive and be independent if they have job opportunities, accessible housing and simply be able to participate in the community more

> *"When you see me, look at me. I look completely normal on the outside. But myself, my brain, my body are anything but normal. It's hard to not look injured but be severely different than who you remembered you were before. Our brains are insanely amazing and extremely stubborn. And it's intense to feel the physical pain from neuropathy constantly and not have found a way yet to decrease that painful feeling that runs down my arms all the way to my fingertips. I'm trying to work toward retraining my brain to how it worked before, but as frustrating as it is to even my twins that I'm NOT THE SAME it is one hundred times more frustrating to me."*

> *"Individuals with brain injuries are not intellectually disabled and should not be treated as such. The nature of brain injury is complex and as such symptoms may touch every part of an individual's life in a detrimental manner. Survivors did not ask for the injury and while at times these individuals may exhibit maladaptive behaviors they are no more in control of the behavioral psychosocial manifestations of their injury as they are in control of the physical aspects of their injury."*

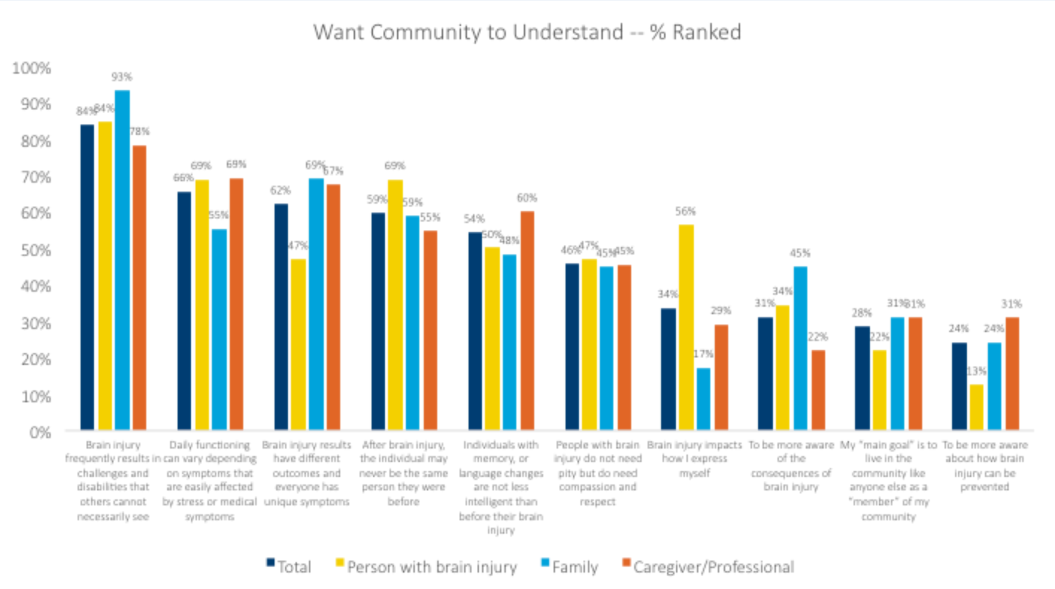
> *"Communities need to become more welcoming and supportive. We need more affordable and accessible housing. It should be on bus routes. Persons with brain injury could have more choices where to live and where to go out."*

> *"People with BI can be successful with the right supports just like anyone, work, school, independent living. I think our communities would thrive more if people with BI could work, live, have their needs met, and participate in the community more."*

> *"Having a brain injury does not mean that I don't have any intelligence. I may have difficulty in one specific area and be gifted in another. Often brain injury is mostly invisible and I really try to do the best I can to overcome these problems and be as independent as I can be."*

> *"That it is important to find employment to meet the unique abilities and skills of someone with a brain injury so they are active in community and can earn part of their pay instead of being on disability. And the dollar amount disability lets people keep in their account is way too low. It is at two thousand and has been that amount for at least twenty years when my son started receiving services. Two thousand twenty years ago or more was worth a lot more then than it is now. So saving for emergencies is difficult. Income changes so that changes too."*

Q6: Again, using the list below, which of the following are **most important** to you when it comes to what you want your community to better understand about brain injury?



Desire for community to understand that brain injury effects cannot necessarily be seen is the most frequently ranked option for all groups

Q12: Now, let's talk about medical and rehabilitation brain injury providers (doctors, nurses, physical therapists, occupational therapists, etc.). As you think about your experience with these providers, talk to me about what you would like them to better understand about <u>mental health as it relates to brain injury</u>.

"There isn't a day that goes by where I don't experience pain, but I act out the pain in a way that it appears to be depression or despair."

"They need to learn the basics of brain injury compared to, for example, depression. They treat the mental health issue but may not recognize how to treat the brain injury."

"My sister needs ongoing and repetitious help to initiate real change. Her occupational therapy was years ago but she retained nothing from it. I can only get her to follow through with things by bugging her constantly about it. That is tedious. I often just give up."

<u>Mental Health as It Relates to Brain Injury</u>

Struggle With Explaining Issues – can't always find the words to communicate issues; not trying to be rude – just need patience – this is hard, overwhelming and makes them feel defeated at times

Affects Whole Body – difficulty with stuff like memory loss/recall, but also trouble physically with how to walk/feed self; look into rare issues and understand full-body impact, not just piece by piece

No Two Situations Alike – don't always fit into some nice, need category; not "just like other patients" – no two injuries are the same; require more time and custom care; need to be seen more frequently

Mental Health and Brain Injuries Can Be Linked, But Also Separate – know how to treat both and be better educated on differences; further, mental health issues can precede a brain injury, too – not everything is because of injury

Need Repetition – help needs to be ongoing and repetitive – repetition helps you learn/understand what is being taught

In Their Own Words—How Mental Health Relates to Brain Injury

Q12: Now, let's talk about medical and rehabilitation brain injury providers (doctors, nurses, physical therapists, occupational therapists, etc.). As you think about your experience with these providers, talk to me about what you would like them to better understand about <u>mental health as it relates to brain injury</u>.

"That the patient needs to be seen regularly and frequently in order to foster change, based on need for repetition, of encouragement, to make necessary changes and seeking to increase the positive behaviors while working on eliminating the negative behaviors."

"A BI affects every cell in the body. You are constantly struggling to resolve what you think and what you body does. Often with BI [you feel like] you go to sleep you were normal and wake up you are not. It's akin to PTSD in many ways. It's traumatic and remains with the person for their entire life. In our case the trauma is relived every night."

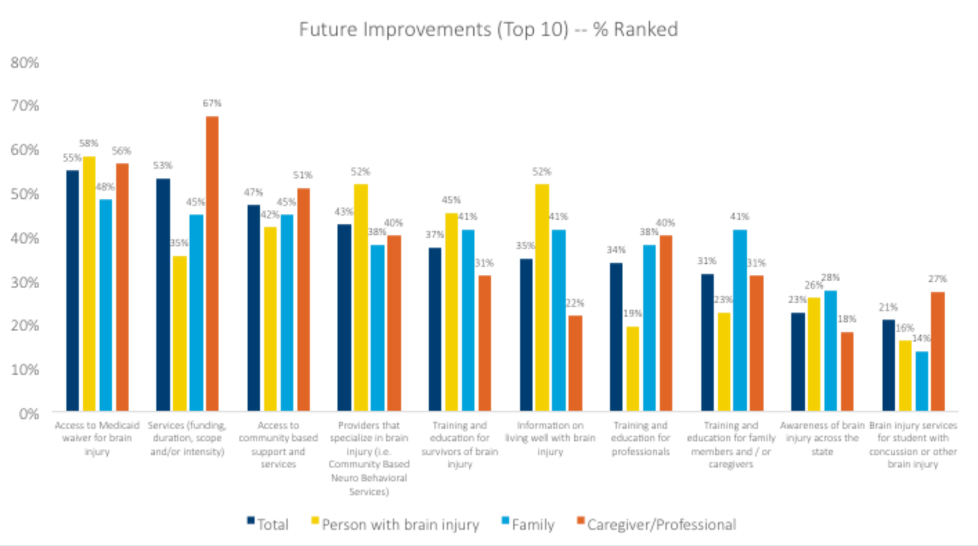
"I would like them to better understand how brain injuries and multiple brain injuries affect the 'higher functioning' patient. Also that they would research any rare conditions caused by brain injuries when the patient has them. That they would treat the patient as a whole person, not trying to piece that person apart."

"They are clients and need to be treated as such. Clients that may need more than the hour window of your time. Maybe your perception and your reality of a client is wrong and what back ground you bring to the table doesn't always apply to that person. People with brain injuries are all different and all need addresses as such. Each injury is unique and what worked for one client may not work for all."

"Preexisting mental health care issues and their impact on brain injury issues. Better information provided to family members and guardians. Lack of communication between professionals providing care and family members. All seems to be filtered through care providers and may or may not reach family members/guardians."

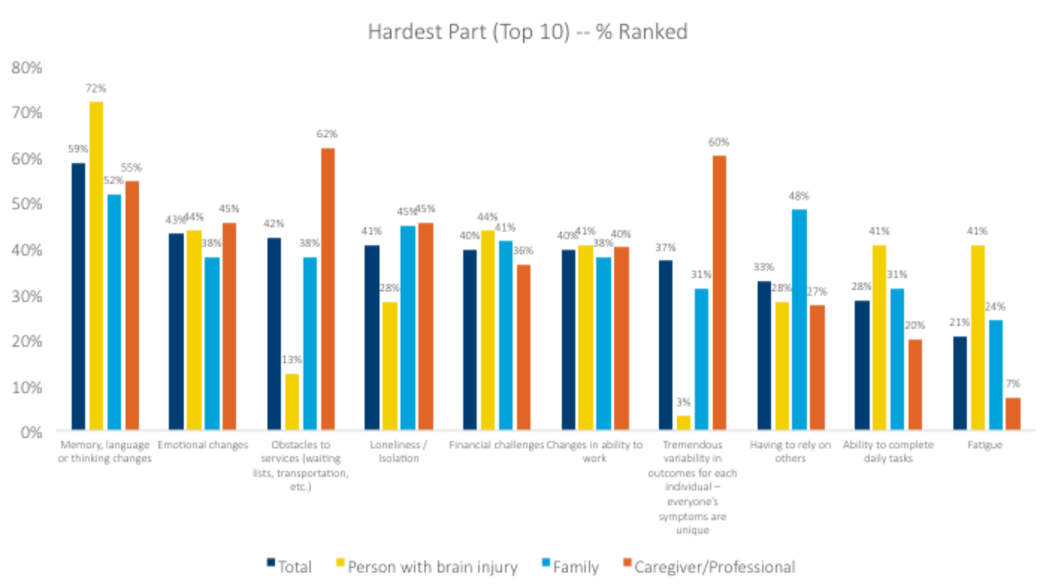
"I need clear written instructions planned at my visits. Know that it affects the whole body, not just one part – I went to general PT for a while to help with balance issues. I later was sent to PT that specializes in brain injury and they were able to help me far more – it was a full vestibular issue and a vision issue as well, not just strength and balance exercises alone. The education difference between the two was phenomenal. Primary physicians and nurses need to know more about the specialist resources available too – why wasn't I sent to the PT specialist in the first place? They need to be informed or else they won't even know to send their patients there to get the help they need."

Q16. What would you like to see improve about brain injury services in Iowa?



Access to Medicaid waivers and improvements in services are most frequently ranked for future improvements

Q18. In your opinion, what are the hardest or most challenging things about brain injury? You may rank **up to 5 options**.



Memory/thinking and emotional changes are the hardest part of brain injury; some key differences across person type, including those with a BI citing fatigue and ability to complete daily tasks higher than others

Q25: We have talked a lot about what you would like others to know more about relative to brain injuries. Now I'd like you to imagine that you could speak directly to those in charge of creating public policy and services for those with brain injuries.

Invest in Quality Providers
You're just throwing money at it without results if providers don't have the right training; you'll spend more money in the long run in care if investment not made up front

Improve Waiver Program
Needs more funding and more slots; reduce wait time to get people the help they need right away; remove monthly cap

Emotional Plea
This is hard, overwhelming, and depressing – for both patient and family; could happen to anyone – don't just wait until you are affected to care; listen to those affected and really hear them and understand

More Brain Injury Specific Assessments
Every injury is different – need assessments that understand and account for that; brain function impact will vary – assessments that fit levels of severity; assessments don't always reflect needs of those with brain injury

Easier Applications For Services
Should be streamlined/simplified – could even be automatic after diagnosis; asking someone with a brain injury to coordinate all the paperwork can be burdensome and unrealistic

Misc. Other
More access for Rural Iowans; help getting job/keeping one – i.e. transportation; more info for families on how to deal with loved ones; work with other states to get ideas of what works

In Their Own Words—What Would You Say to Policy Makers

Q25: We have talked a lot about what you would like others to know more about relative to brain injuries. Now I'd like you to imagine that you could speak directly to those in charge of creating public policy and services for those with brain injuries. Let's say you were a key advisor. What would you say to them to make policy and services better for you?

"The waiver system needs to be redesigned to better meet the needs of individuals with brain injury. The most impactful time frame for rehab post-BI is within the one year after BI. Current state is a waiver waiting list well beyond this one-year time. When individuals do receive waiver funding they are past the appropriate time for rehab. Individual outcomes are not as good as if services had been provided at the appropriate time."

"I have worked with the BI population for the HCBS waiver for eleven years. I would first address the assessment piece that is completed for a person who is applying for the BI waiver. The assessment tool that is currently being used does not reflect the needs of the individual with a BI. Other assessments tried have not reflected the needs either. Nothing is more frustrating than knowing that the person you are working with needs assistance but is denied due to the assessment not reflecting the need."

"Continue to monitor what is occurring on a national level. Reach out to other states to see 'what works' and 'what doesn't.' Listen to individuals who have been impacted by a brain injury. Listen to individuals and healthcare providers who are passionate about brain injury and present services that protect Iowa citizens."

"More funding to qualified service providers. Focus should be on service providers who invest resources to educated professionals who demand a higher quality of services. Throwing money at the same poorly equipped service providers typically SCL providers who hire high school educated staff will reap absolutely no benefit. My observations are that these staff do not have the skillset which then results in the system failing the brain injury survivor."

"Understand how overwhelmed families/ individuals affected by this are and try not to add more hoops to jump through and paperwork or phone calls to be completed just to get the services needed."

"Providing easier access to services within the communities opportunities to socialize with community members increase training and education for professionals."

"They need to better understand the devastation a brain injury can create in an individual's life and his or her family. There needs to be services available to help the survivor and family have the best outcome possible. Easing accessibility to the BI waiver for both children and adults."

Q28: We have talked a lot about what you would like others to know more about relative to brain injuries. Now I'd like you to imagine that you could speak directly to those in charge of creating public policy and services for those with brain injuries. Let's say you were a key advisor. What would you say to them to make policy and services better for you?

"It is insanely discouraging to us brain injured that we are not the same person we once were. We want to remember things again to know things again. It would be incredibly helpful to have brain injury advocates in our corner letting us know what services are out there available to us. To have access to programs and to have your case worker knowledgeable about what programs are available and help us apply to and for them."

"This could happen to anyone in your family. You can be rich, poor, young, old. It's easy to look away until it happens to you. One may look absolutely 'normal' on the outside but looks are deceiving. People with TBI's need services and support. FAMILIES OF THOSE WITH TBI'S need help. Your whole world turns upside down. As a social work I would ask for Brain Injury Waiver slots. As a wife I would ask for an expansion of voc rehab services."

"Brain injury support is just as important as services for individuals with disabilities or veterans or the elderly. BI survivors are often unable to complete the simplest of tasks without assistance. Why should they be denied that assistance?"

"I would like all those in charge to understand that we had full lives before our injuries that doesn't stop or slow down when we have a brain injury. As a single mom without a family support network I'm constantly reminded that my son is a kid vs a caretaker who is now dealing with his own mental health journey at orchard place as a result of having a stroke at 36 years old. Not one day goes by that I'm not juggling my physical health recovery along with my sons mental health recovery."

"Ask those with brain injury instead of just thinking this or that is what they need. Listen to what the family has to say about needs also. Think of what it would be like if you have a brain injury and how it would affect you. Then do what is right to help those who live with brain injury."

"I would let them know that this is a very individualized injury; not everyone experiences the same symptoms or healing on the same time line. Symptoms can be debilitating and life changing even though the individual may 'look fine.' An experience like this changes the individual and the family. Medical professionals need more training and there needs to be more support available for individuals and families."

Additional Findings

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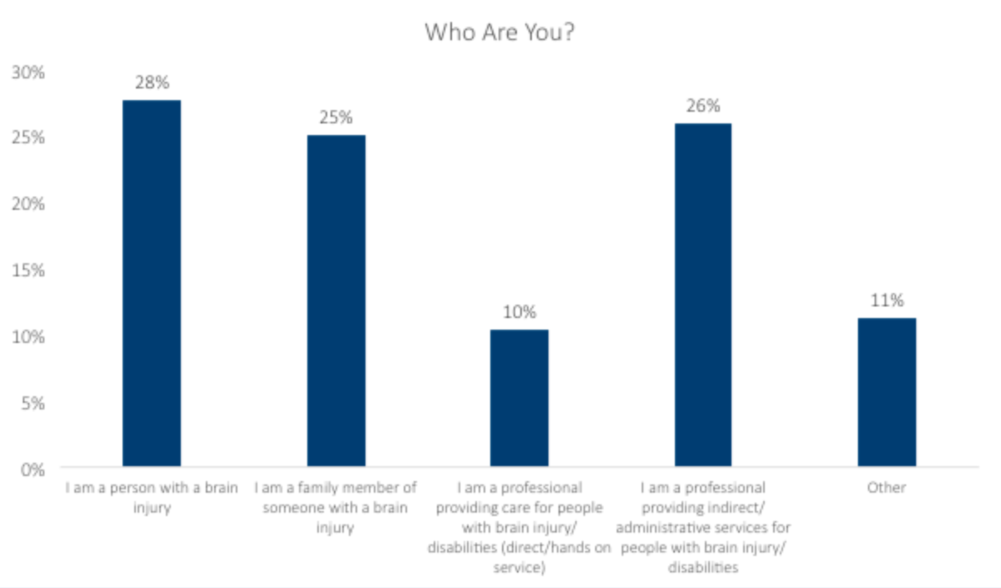
Q1: Please help me get to know more about who you are by selecting which of the following statements apply to you.



Sample is split between those with a brain injury, family, and professionals providing indirect/administrative services

Q3: Let's talk about disability service professionals (i.e. case managers, service coordinators, direct care staff, home health aides, etc.). As you think about your experience with disability service professionals, talk to me about what you would like them to better understand about brain injury.

Educate Case Managers
Feel they don't know enough about brain injuries – how each individual is affected differently or all the services available to effectively and compassionately do their jobs

More Training/Education on Everything BI Impacts
Want service professionals to have a greater understanding of all the aspects that brain injury can impact, not only so they can take better care of individuals, but to increase compassion and understanding; sensory processing, emotional/mental health, difficulties remembering instructions, even financial roadblocks

Not All Brain Injury Cases Are the Same
Educate service professionals on how individual are impacted very differently; a "cookie cutter" approach will not work; all individuals (and families) need a personal assessment to understand their specific needs

Just More Patience and Understanding
They acknowledge that caring for someone with a brain injury can be challenging, but want to encourage understanding that these challenges are due to physical or emotional impacts as a result of a brain injury

Q3: Let's talk about disability service professionals (i.e. case managers, service coordinators, direct care staff, home health aides, etc.). As you think about your experience with disability service professionals, talk to me about what you would like them to better understand about brain injury.

In Their Own Words— What Service Professionals Should Know

"That every injury is different and the outcome in which someone experiences a brain injury is different. Therefore, services must be personalized and individualized. Services cannot be cookie cutter in order for them to be successful. Identifying barriers that a specific individual has goals they have and skills they want to develop and a plan on how to get there has to be person-centered based on their skills, challenges, environment, and support system they have access to both natural and paid."

"Everyone's recovery is different. What may work for one person with the same injury may not work for someone else with the same injury. It might work some days but not other days or it might work in the morning but not afternoon or this works in the early part of the week but by the end of the week something else is needed."

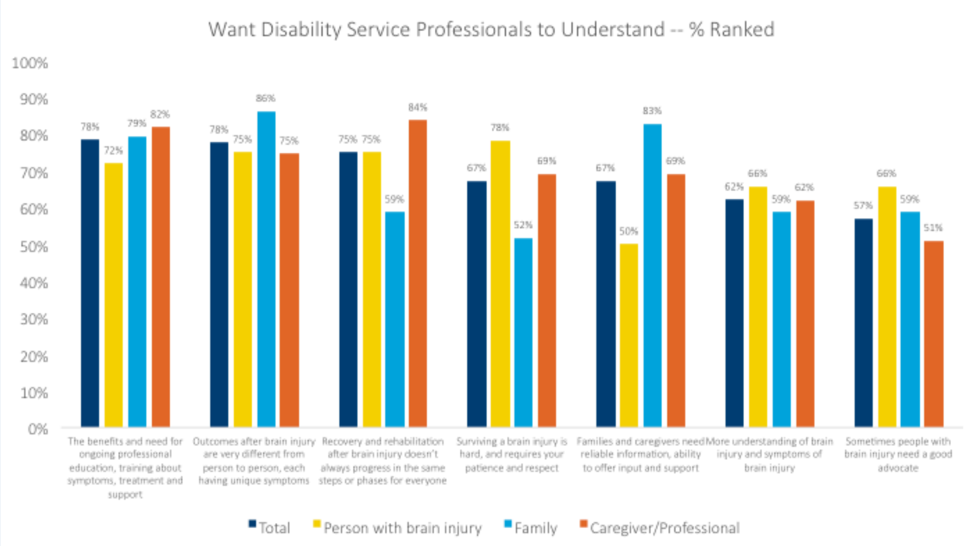
"I would like others to understand that no two brain injuries are the same. What may work with one person with a brain injury might not work with another. It can be frustrating when assisting new persons learning how to work with persons with brain injuries and they keep asking why did you do it one way with said person but not with this person. Brain injuries are not cut and dry; they are all different. Same as persons are all different."

"New case managers associated with the Managed Care Organizations have limited knowledge on brain injury or services required. We wish they would take time to learn more and also respect those who have industry experience in this field."

"The variety of services/organizations available to help. The 'mental fog' that goes with brain injury and how that affects getting things across to them at office visits as well as understanding remembering instructions given at office visits. The road blocks that we face financially - not only with medications and health care but also with transportation, food, home, bills, etc. - and the added stress that puts on us during a time when we are already struggling."

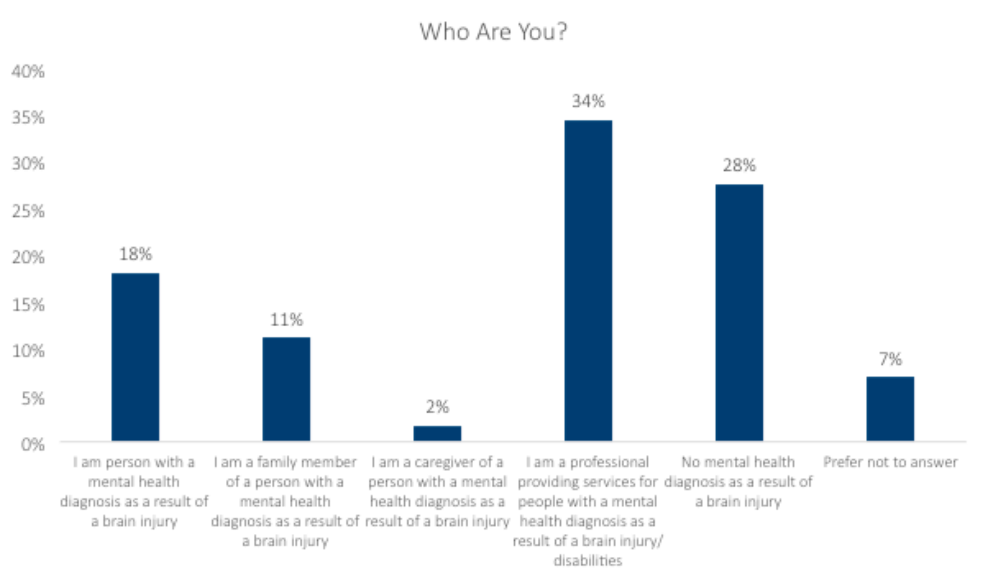
"My case manager through my insurance has come out once but doesn't have a lot of knowledge about my particular brain injury and what services I can get that would actually benefit me. Knowledge about particular brain injuries would be helpful, I believe. I'm very motivated to relearn life again and to find different ways to help me deal with my physical disabilities. It would just be nice to be able to turn to my case manager and asked the questions I have at that moment. And for them to be able to recommend different covered services that would actually be beneficial to my brain injury and the physical defects it left me with."

Q4: And, using the following list, which of the following are most important to you when it comes to what you want disability service professionals to better understand about brain injury?



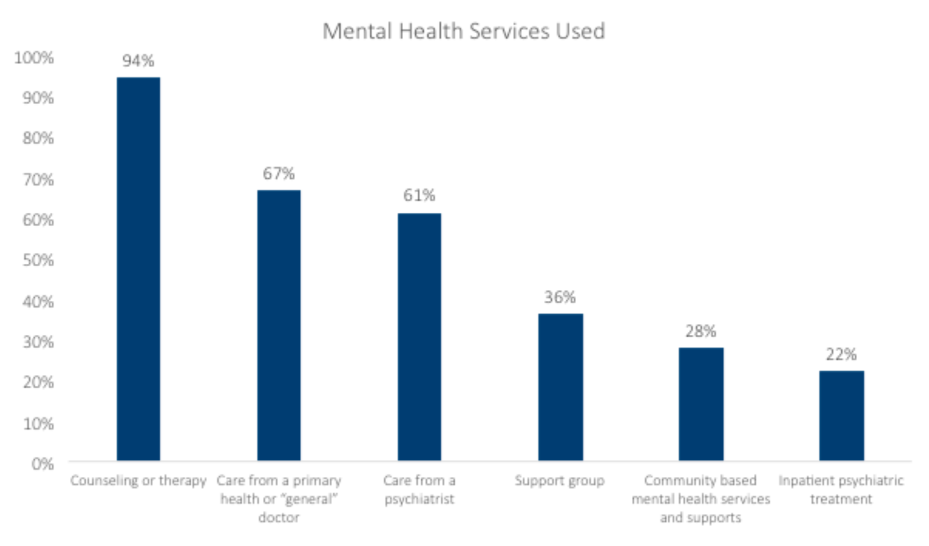
All options are ranked in the top 5 at least 50% of the time, with need for ongoing education, outcomes/rehab not being the same for everyone as most frequently ranked

Q7: I'd like to know a little more about you. Tell me, which of the following statements best describes you?



Approximately 2/3 of the sample indicate some connection to mental health diagnosis because of brain injury

Q8: Since **[insert your/your loved ones/those you care for experienced a]** brain injury, have **[insert you/they/they]** used any mental health services and support?



Those with mental health diagnosis due to brain injury report using counseling or therapy almost universally

Q9: First, let's focus on mental health providers (counselors, psychiatrists, psychologists, etc.). As you think about your experience with mental health providers, talk to me about what you would like mental health providers to better understand about brain injury.

What Mental Health Providers Need to Understand

Remain Positive – this can be intimidating; hard to know your life will never be the same; "crave the old me so much;" BI leads to depression and anxiety that is very real; not trying to be moody, it's just really hard; listen and talk directly to me – not just a caregiver

More Than Just Medication – brain injuries affect how medicine works too; need to learn how to deal with it, not just keep taking medications; need the right treatments for injury – and sometimes those need to be more challenging than what they are

Reduce Stigma – use same codes on forms as other mental health issues; "I'm broken, not crazy"

Expand Knowledge – some providers can be dismissive of the injury or symptoms; get the runaround between departments (i.e. neurologists/psychiatrists) – don't know enough about the other side

Need More Providers – not enough providers and can be difficult to get an appointment

"It's so intimidating to not know things, to know your brain isn't working correctly. For the mental health providers to just remain positive and knowledgeable is very supportive."

"The uncertainty and the fact that I can only benefit through therapy by learning how to live with my impairments. That it's unlikely you will be healed. I crave the old me so much. So it's difficult for us to understand that they are there to help us adjust and to manage our lives and emotions the way life will be from here on out."

"Understand that a BI is very different from MH. The diagnosis may be the same but presentation may be different. Treatment may be very different especially medications. The body metabolizes medications differently after a brain injury."

In Their Own Words—What Mental Health Providers Should Understand

"Professionals use the same diagnostic codes whether the mental disability is caused by a brain injury or an organic reason. They label the person with the brain injury in ways that are not helpful to the family or survivor."

"There aren't enough psychologist and psychiatrists in my area. Waiting time for initial visit is too long. Suicide hotline basically says go to your emergency room, which will not have a quality person to help."

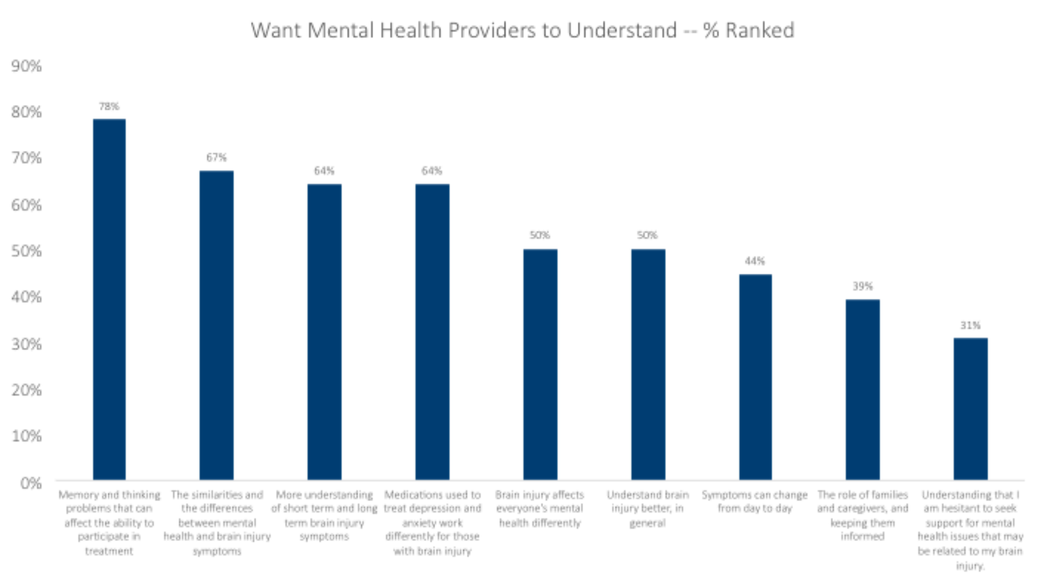
"We're not complaining. Rather, we are voicing our experience as best as possible. We don't mean to be moody. Please understand migraine pain is horrible and I use cannabis as a medicine, not as a 'drug' to get 'high' on. It works as a pain reducer so I use it. Period."

"It is difficult for us to accept our new normal. Our deficits cause a lot of depression and anxiety and frustration. Anxiety affects every part of our everyday life such as just getting through the day getting done what needs to be done and making decisions and choices, even having a friend come over for a visit and leaving the house for a medical appointment or going grocery shopping and even answering the phone."

"The psychiatry department said she would be better served in neurology but neurology wouldn't see her because she didn't have seizures so we went back to psychiatry and they said they would take her because she needs care for her brain injury. We had sought out this care for her after being told she needed doctor care to follow her brain injury after a neuro-psych evaluation that was required to determine if she was eligible for brain injury waiver at age 20. After a year of follow by a psychiatrist, she referred our daughter to a neurologist who asked her a question that really irritated her and she got angry. The neurologist told her she was a spoiled brat and our daughter had a major meltdown. The neurologist didn't understand brain injury and told us that there was no help for our daughter and we should not put up with her behavior and put her in a facility. So she went back to psychiatry and has been receiving on-going counseling and is doing pretty well with that but she doesn't like the misunderstanding that she is perceived as mentally ill when she goes to the ER."

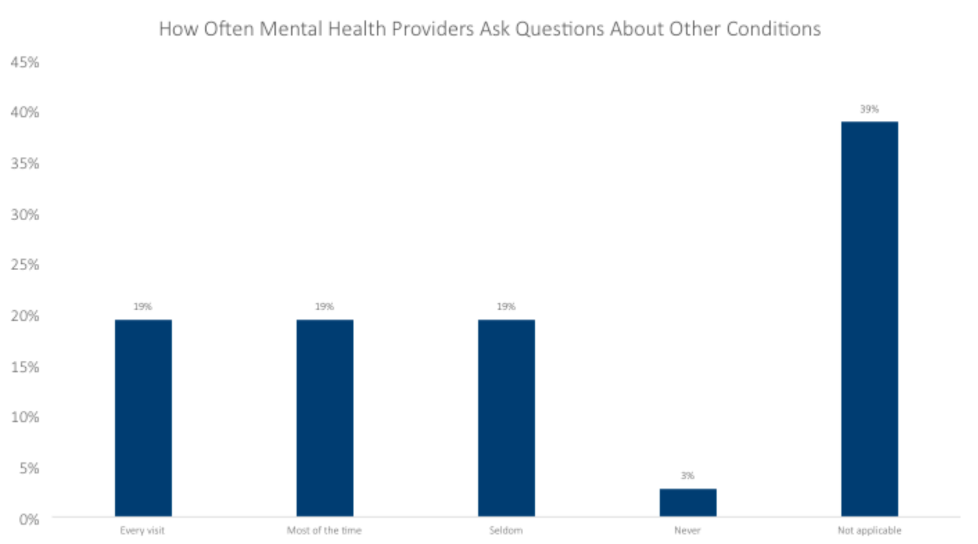
"Sometimes I think that they are a little dismissive of some issues that are concerning and relegate them to getting older when I do not think that is the case. So I don't feel that i am being helped dealing with the loss of certain abilities."

Q10: Just to make sure I understand, using the following list, which of the following are **most important** to you when it comes to what you would like mental health providers to better understand about brain injury?



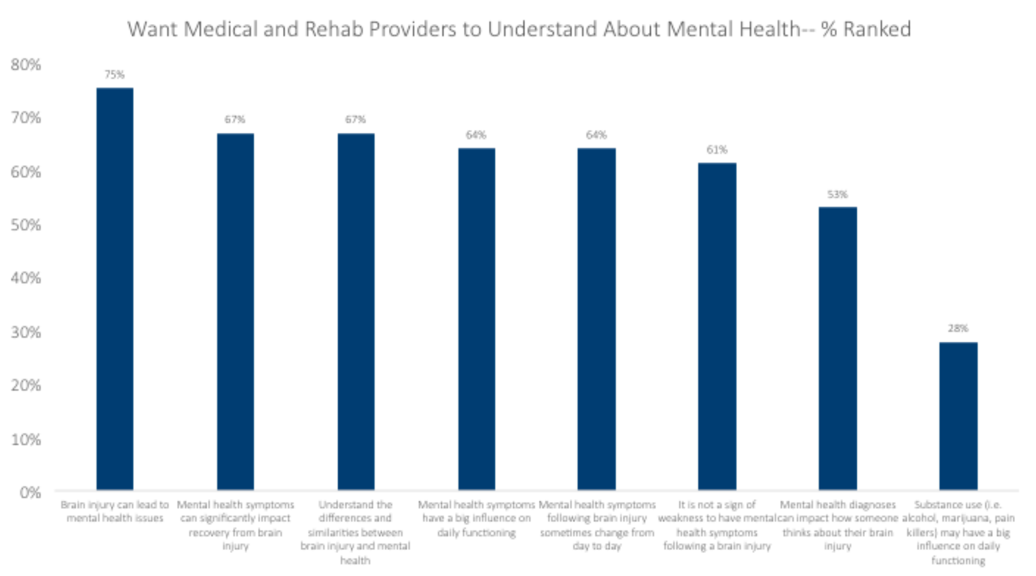
Those affected by a mental health diagnosis want mental health providers to understand memory and thinking problems affecting ability to participate in treatment

Q11. How often does your mental health provider ask questions about other conditions you might be experiencing, such as brain injury, substance abuse, and physical conditions?



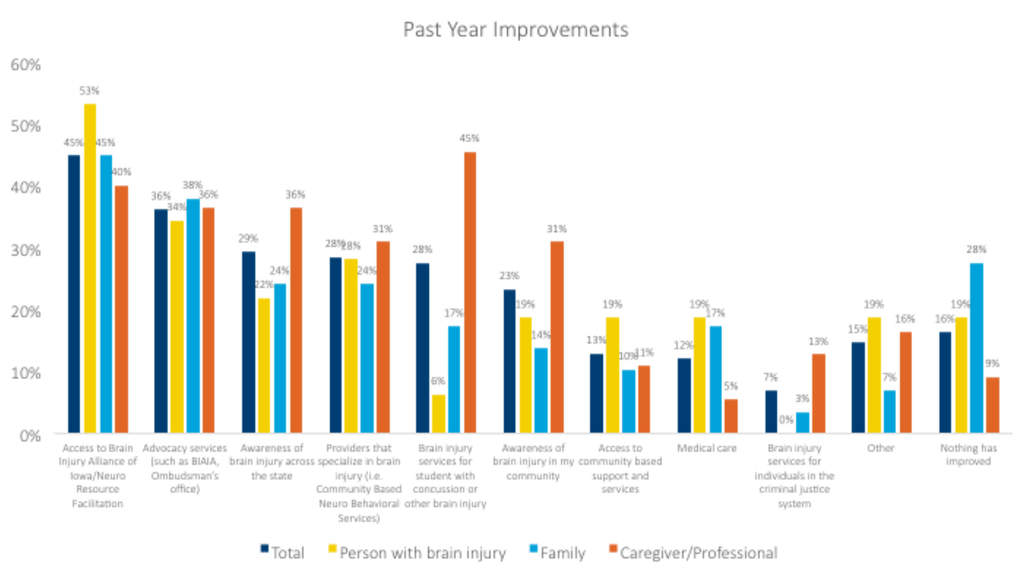
Of those who see mental health providers, split evenly among being asked about other conditions on every visit/most of the time/seldom

Q13: Using the following list, which of the following are **most important** to you when it comes to what you want medical and rehabilitation brain injury providers (doctors, nurses, physical therapists, occupational therapists, etc.) to understand about mental health?



The most frequently ranked option for brain injury providers to understand about mental health is that the injury can lead to mental health issues

Q14: Now, thinking about brain injury services in Iowa, which of the following have <u>improved</u> in the past year?



Most commonly cited improvements include access to Brain Injury Alliance/Neuro Resource Facilitation; family are most likely to cite nothing has improved

Q15: I am sorry to hear that you feel nothing has improved in the past year. Help me understand why you feel that way? Tell me about the struggles you are facing relative to these services.

1

Issues With Medicaid: uncertainty with the program; worried about privatization; not a lot of confidence in program

"There is a LOT of uncertainty in Medicaid and case managers have changed multiple times. Not a lot of confidence in stability of services."

2

Not Getting Help: issues with case managers not getting assigned, services have been denied; not enough waiver slots

"All they could do was send me pamphlets but I was looking for a case manager, someone to coordinate services for me where I could go for help with healing."

3

No Conferences/PSAs: not aware of any conferences or public service announcements being made/held in their area

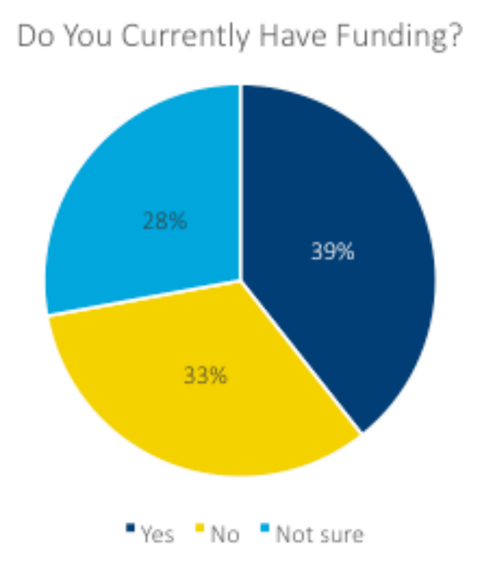
"I have seen no conferences, no PSA for awareness in the last 12 months. Some things for kids but not adults. No flyers. Lots of doctors do not even screen for mild brain injuries or track changes in behaviors."

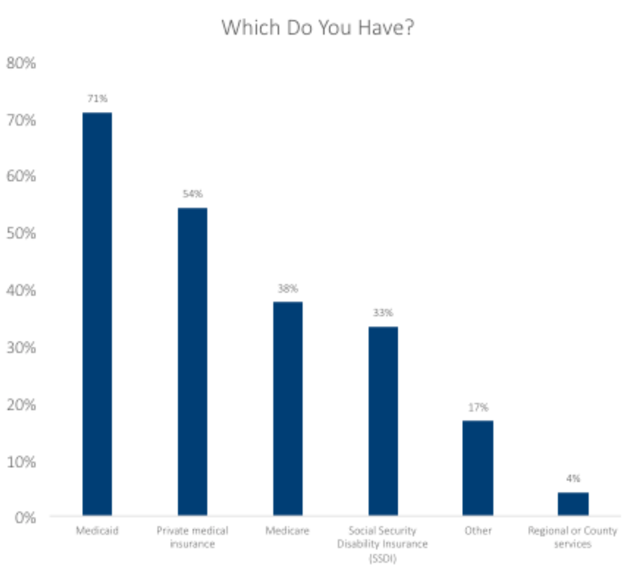
4

Other Misc. Mentions: poor experience at a nursing home with care; want to see more facilities around state; not getting worse, just not any better

"My journey included a two-month stay in a very bad nursing home. I've never felt so helpless or hopeless before. I had no advocates or help. It was a very bad experience that felt like it would never end."

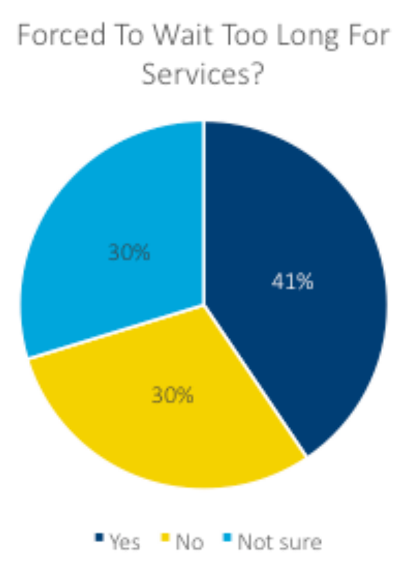
Q20. Do you currently have funding for services?
Q21. Which of the following do you have?

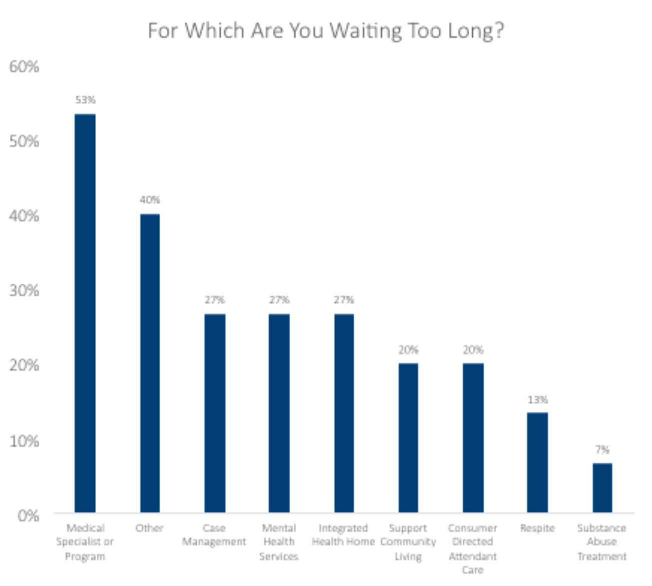




About 40% currently have funding for services, with 71% of those with funding having Medicaid

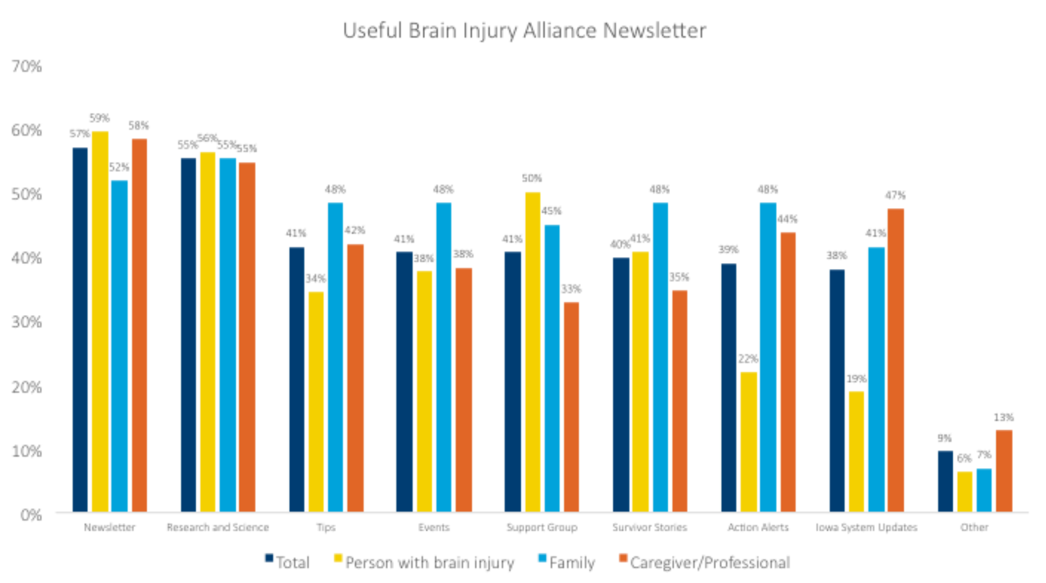
Q22. Are **[insert you/your loved ones/those you care for]** forced to wait too long for needed services?
Q23. For which services are **[insert you/your loved ones/those you care for]** waiting too long?





Just over 40% are waiting too long for services, with a medical specialist or program the service most frequently waiting for

Q26. What information from the Brain Injury Alliance of Iowa newsletter, social media, and electronic mailings do you find useful?



The newsletter and info about research and science are found to be most useful information from the Brain Injury Alliance

Q28: Thank you for all your help today! Before we wrap up, I wanted to give you one last opportunity to tell me anything you feel is important to know about brain injuries that I haven't already asked you about.

What Else Would You Like To Say?

- This is Difficult – life will never be the same – not just for the one injured, but for family and friends as well; just trying to cope and adjust to "new normal" – some days better than others; those with BI know it's frustrating for others too, and that makes it even more difficult to bear
- Appreciate Support from BIA – forms and paperwork are difficult and Brain Injury Alliance helps guide them; don't know where they'd be without BIA
- Should Be Easier to Get Help – not enough providers or funding; takes too long to get help; forms confusing
- Resources For Families – families need help with how to deal – especially right away; families don't know what they're getting into
- More Education for Providers – all levels of doctors should know how to treat/interact with those with BI
- More Student Education – educate younger people how to recognize or deal with those with BI; in youth sports, reduce stigma so kids know sitting out is not a punishment

"The work that BIAIA is doing for individuals with BI and families support systems with BI is great."

"Increased awareness and funding are some of my top priorities. I struggle to support my individuals due to lack of funding. In conjunction with that lack of funding I then have a limited amount of available resources to utilize when funds are not in place."

OE: Thank you for all your help today! Before we wrap up, I wanted to give you one last opportunity to tell me anything you feel is important to know about brain injuries that I haven't already asked you about.

"I'm grateful for NAMI and Iowa Brain Injury Alliance. With out them I would be a mess. I feel central Iowa lacks what Iowa City/ Coralville has. It seems more is going on for caregiver training and seems to be more in general going on for participating in various activities in that area chapter. More awareness that Brain injury isn't a death sentence and your loved one needs brain therapy and with the proper care they can live a filled happy life. They may not ever be as they once were, but they can be happy and healthy."

"Sure wish my husband had worn a helmet that day. Our whole life changed. Now we have a new life that we are making the best of. Our faith is strong. We have much love. It just needs to be easier to acquire help and services."

"I think more education in high schools would prepare society to better understand BI and it would eventually change the understanding of BI throughout the community."

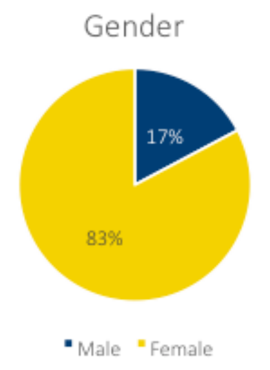
"People with brain injuries are still human beings. The injury does not rob them of their soul. How they're treated after injury can be what either makes or breaks them. What would Jesus do?"

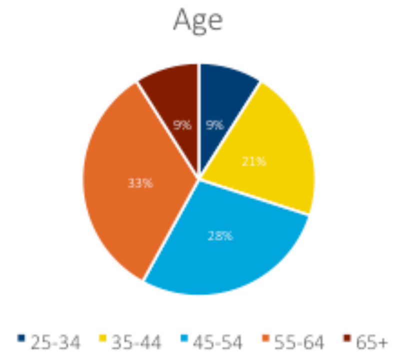
"Providers need more education on how they can work with people with brain injury and to know that people with brain injury are not trying to be more difficult but that their brains are just needing more support."

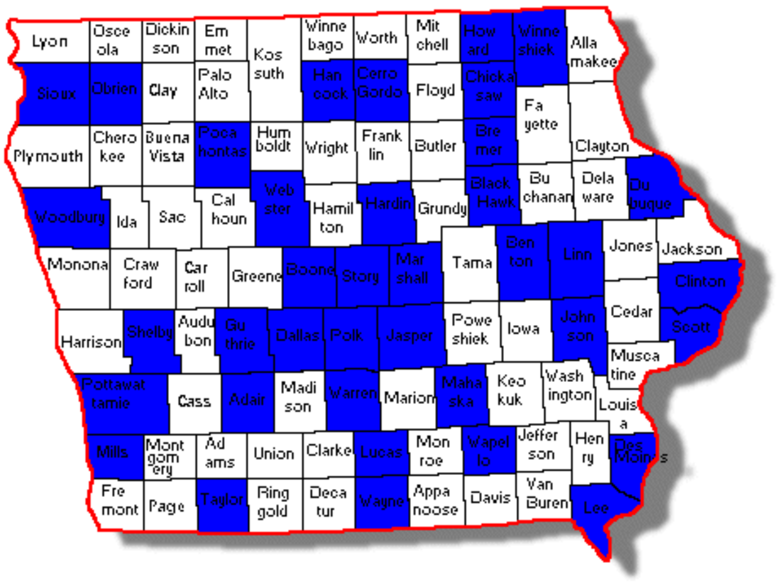
"I could probably blabber on all day about what I've gone through and tell some of the funny stupid things I have done. It has taken a couple of months for my wife and I to communicate better and not get angry about my errors or her directions. As the good book says, patience is a virtue."

"I appreciate the support your organization has provided my family. Brain injuries are horrible and life changing. They are confusing and unpredictable. No one knows a lot about brain injuries except those that have experienced and each is very individualized. People don't understand the changes it brings into a life lives. Knowing someone with a TBI is like knowing someone with autism: no two are alike. We need to increase awareness."

D1: To wrap up today, I have just a few questions that will help us better understand who and where you are.
D2. What is your age?
D3. What is your gender?







For More Information

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