

2020 Needs Assessment



What Brain Injury Survivors and Advocates Want You to Know

Survivors of brain Injuries (BIs) need patience, understanding, compassion, and respect, not judgment

BIs are often invisible, but frequently result in challenges and disabilities as real as a broken arm.

Nearly **80%** of respondents want you to know **all BIs are unique** and require individualized treatment plans.

It is important to understand the **similarities and differences between mental health and BI symptoms**, as well as **short- and long-term BI symptoms**.

Challenges for Iowans with Brain Injuries

55% of respondents this year noted **financial challenges** as one of the most difficult part of having a BI, with only about **1/3** receiving funding for services



Memory, language, and/or thinking challenges for the past four years have been ranked as some of the most difficult parts of having a BI, along with **emotional changes**.

How You Can Help – Advocate For:

More training on BIs for new doctors and providers.

More providers in rural areas, traveling doctors, or transportation for rural patients.

Each TBI is different, so **services and funding need to account for variety in recovery progress**.

More support/resources tailored to less severe cases, such as those suffering from post-concussion symptoms.



“Prevention and quick treatment and rehab are very important. Quality care in the beginning will lead to greater quality of life in the years to come. It will also be cost effective to help those with brain injuries become more self-sufficient.” – Survey Respondent

More resources/support system for family members.

Cut red tape that causes delays in getting funding/ service that can hinder recovery.

De-privatizing Medicaid - Iowa survey respondents feel privatized Medicaid has been harmful and made it more difficult to get funding/support, and **53% desire improved access to Medicaid**

Need **more public awareness** – realize those with TBI are still people who just want to be part of the community and contributing members of society, but sometimes struggle.



Objectives and Methodology

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:

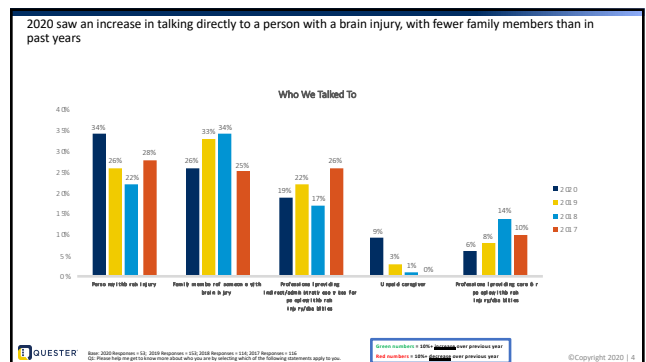
- What are the top needs of those with a brain injury?
- What do they want key stakeholders to understand about a brain injury?
- Barriers to receiving services
- Compare key metrics year-over-year

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

All respondents had some connection to brain injuries and services

Achieved 18 completes from those with a brain injury, 14 from family members of those with a brain injury, 18 from professionals providing either direct or indirect care, and 3 from "Other" relationship

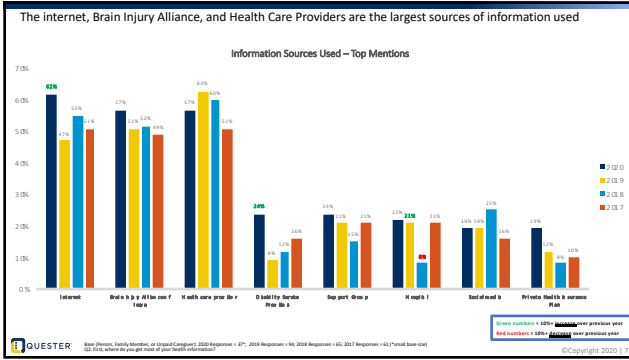
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Key Takeaways

- People want policy makers to cut red tape – especially early in the process – they need to know how important the early stages after a TBI are to the recovery process and how vital it is to get on the right path with early rehab**
- 70% Think Assistive Technology Would Be Helpful**
I wish [professionals] had more patience and understood that this is a long-term, invisible struggle. As a caregiver, I find myself frequently having to advocate on my child's behalf. I think people don't understand the journey that we have been on prior to getting to them. They need to take the time to understand that.
- Financial Challenges came out as the most ranked Hardest Part of Brain Injuries**
 Possibly related to COVID, as most other items were ranked similarly to past years
- Access to Medicaid Waivers most desired Future Improvement**
- Many Continue to Plea for Patience**
 It can be tough communicating with a TBI patient, or having them remember something – please be patient with them and know they are trying
- Neuro Resource Facilitation is Improving**
 53% cited it as a past year improvement in 2020, up from only 35% in 2019
- Mental Health Providers Need to Understand Short & Long Term Symptoms**
 This saw one of the largest year-over-year increases, going from 43% in 2019 to 70% in 2020

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Community members should understand that brain injuries are often invisible, and while people may look normal, they may never be the same and have constant struggles

What Should the Community Understand?

BI is Often Invisible

- People with BI often look normal, but they have limitations you cannot see
- No crutches or bandages, but the way their brain processes info has changed
- This can happen to anyone, so you may not even know someone is a survivor unless they identify themselves to you
- Manifests itself more as memory loss, emotional swings, and being able to say the right thing – clear in their head, but words don't come out right

Will Never Be The Same

- This is something that will be with them for life – recovery is long and slow – they may never be the same person they were before
- This impacts every second of every day and can be difficult to cope with – even impacting someone's pride or dignity knowing they are a different person and may never fully recover

Need Compassion & Patience

- Community needs to know that just because they are injured and different than before, that doesn't mean they lack intelligence or are "stupid"
- Need compassion and patience – continue to be a good friend and neighbor and help with things that they struggle with
- Need understanding and to not belittle people with a TBI

Impacts Interactions with Community

- Brain injuries can cause difficulty with those someone interacts with others or the community at large
- Emotional swings can occur, as well as a lack of focus – but that doesn't mean they are "bad or non-compliant"
- They are trying their best, but emotional events can be triggered, or they might struggle to pick up on social cues

QUESTER | Brain Phos, Family Member, or Hospital/Clinician? 2020 Responders = 137, 2019 Responders = 84, 2018 Responders = 64 (Full-time base only) | ©Copyright 2020 | 1

What the Community Should Understand – In Their Own Words

“That people who experience an injury will not be like they were prior to their injury, and that a person's brain has been forever changed. The fact that the brain will mistake and process things differently due to the injury.”

While a brain injury may not be as noticeable as a traumatic injury – no crutches, bandages, or slings, for example – we have some limitations and need patient and sympathetic help with some things.

That we are just like them but in some things we just take time. I have, at times, a problem finding the words I want to say. I can explain things clearly in my head, but getting them out is difficult sometimes and it takes time.

Brain injuries may affect the way an individual engages with the world. Sometimes this leads to the individual being labeled as bad or non-compliant. These individuals need patience and understanding, not judgement.

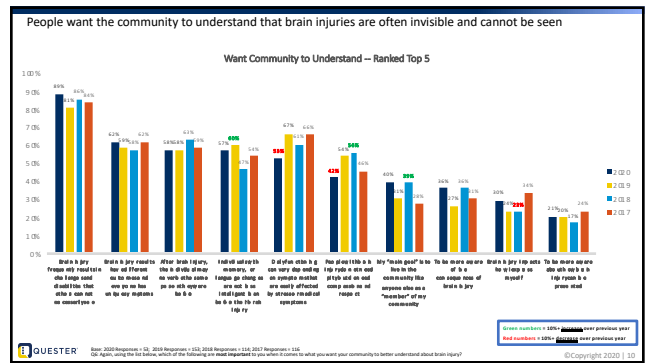
“Personality changes, a wide range of emotions are part of the brain injury. When the individual seems very angry or mean, understand where it is actually coming from. My family member can become passive and angry regarding certain issues. This comes off negatively by most of the community.”

This is hard. My husband has suffered a blow to his ego and dignity. It's difficult being out in public places and events sometimes.

Mostly that just because you have a BI does not make you a stupid person. Sometimes with a speech impediment you may sound like you have been drinking and/or on drugs. Be a little more patient and understanding if the person is practically a little slower than you.

Someone with a brain injury may appear to be able to function at the same level as someone without a brain injury, but that appearance isn't always accurate. They may not be able to do the things that at first seem like they are able to do.

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Brain injury Providers need to show compassion and take the time to really understand what people are going through and how they provide individualized help

More Understanding & Compassion

- Need providers to actually listen to family/caregivers – really understand what they are saying and not dismiss their opinions/observations
- Not everyone has same experience or symptoms – need to understand how to individualize treatment so people get the proper help they need
- Seek continuing education to properly treat people, and understand how certain medications interact with other medicine they might be on

“Many doctors have turned away my clients because they get agitated or angry. They need to UNDERSTAND that can be part of brain injury. They need to learn how to approach and speak with those who have frustration and anger with their brain injury.”

They need to write instructions out, keeping them short and to the point. Remember that when recovering from a brain injury a timeline is helpful, but reminding the patient that each person responds in their own way is very helpful for them to hear.

Take The Time

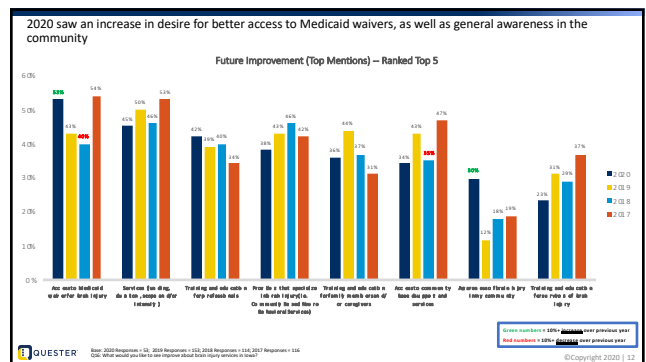
- Be patient with people – really try to understand them and realize how difficult it can be
- Don't react overly if the patient gets agitated or annoyed – people with BI have a difficult time controlling or masking their emotions
- Memory loss is a big deal, so don't get upset if someone forgets an instruction you gave – it would be helpful to have them written down in clear, concise language

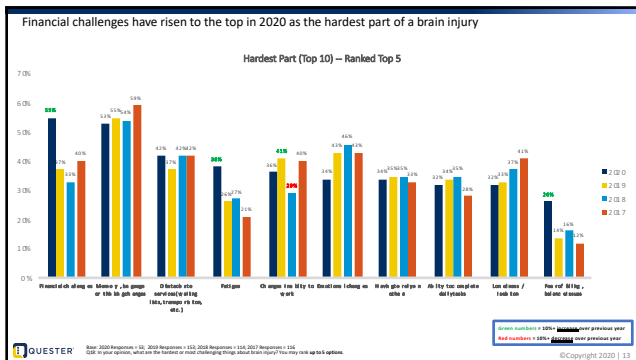
“That mental health issues may or may not stem from a person's brain injury, but mental health issues and brain injury issues are NOT the same and cannot be treated the same. I have never understood why there is so little understanding or education to professionals about the difference because they are huge.”

Brain Injury & Mental Health Are Not The Same

- They are not the same diagnosis and as such can't be treated all the same – don't push aside the mental health diagnosis
- Understand my ability to retain needed information to apply strategies to improve my health is often easily forgotten. Sometimes my providers have been upset or frustrated when I did not complete my therapies not taking into consideration reality of symptoms of my brain injury.

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Policy Makers need to know that quick access to rehab is hugely important, and red tape that causes delays in getting funding/service can hinder recovery

<p>Cut Red Tape/Streamline Process</p> <ul style="list-style-type: none"> Need to cut down on red tape, specifically around waiver waiting lists or caps Streamline the ability to get in to see providers and get necessary resources Early help is key in the recovery process - necessary to get on top of your rehab and get in quickly - it can help with long-term recovery the earlier you start Delays in getting approval only hurt the chances of recovery and hinder the healing process <p>De-Privatize Medicaid</p> <ul style="list-style-type: none"> Feel it has been harmful to towns, and something that has not worked well and made it harder to get support/funding 	<p>Need Individualized Plans, Help</p> <ul style="list-style-type: none"> Each TBI is different, which means people can't be rushed through a system or some standard recovery plan Services and funding need to account for variety in progress rates <p>Resources for Family</p> <ul style="list-style-type: none"> Not just the patient, but families are impacted as well They are often unprepared for what comes next More resources/support system designed for those taking care of family members 	<p>Doctor, Provider Training</p> <ul style="list-style-type: none"> Would like to see mandatory continuing education for health providers Or have more training on TBI as part of licensing/education of new doctors and providers <p>Support for "Less Severe" Injuries</p> <ul style="list-style-type: none"> All TBIs are severe, but it can seem like the focus is more on the more severe cases (i.e. the ones the require more "touting level of care") Want more support/resources tailored to less severe cases, such as those suffering from post-concussion symptoms 	<p>Rural Support</p> <ul style="list-style-type: none"> Need more providers in rural areas, or help with getting transportation for rural patients Or have traveling doctors from the University of Iowa come in and provide services to underrepresented areas <p>General Understanding, Compassion</p> <ul style="list-style-type: none"> Need more public awareness - realize those with TBI are still people - people who just want to be part of the community, but sometimes struggle Help them become contributing members of society - think of funding like an investment
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Message to Policy Makers - In Their Own Words

Prevention and quick treatment and rehab are very important. Quality care in the beginning will lead to greater quality of life in the years to come. It will also be cost effective to help those with brain injuries become more self sufficient.

Those living with a brain injury have individualized needs as far as how long it takes someone to recover and regain skills. Understand that rushing them through rehabilitation due to payment only hinders them, thus costing more money in the long run.

Institute more than cursory training for medical professionals - MDs, DOs, RNs, PAs and so on - regarding the effects, long-term and short-term, of brain injury. Perhaps this could be part of licensing or made mandatory in medical or nursing school programs for example.

Early treatment and rehabilitation will save not only resources, but lives. Returning people to productive living will contribute to the community family etc. Providing services is not a burden - it is an investment.

Talk to the families and give them resources and help them use those resources. Families have zero education prior to their loved ones' brain injury. They are lost and need lots of help. Services should not have to be fought for.

I think there needs to be more focus on those with post-concussion syndrome. There is a lot of focus on those with brain injuries that are very severe but not nearly as much focus on others. I often find myself in a position where we are too advanced for some services but not advanced enough for others.

Traveling Specialists: from the University of Iowa Special Clinics and Family Practice Centers to all areas of the state to train local family physicians and mental health clinic staff and service providers.

Reverse the privatization of Medicaid in Iowa. It has been incredibly harmful to many of the most vulnerable Iowans. That is the one thing that would help people with B.I. and mental health disabilities - the restoration of those services and re-implementation of the way those services were funded.

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ADDITIONAL FINDINGS

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Disability Service Professionals need to realize every patient is unique with different needs, as well as how their internal struggles require more patience to deal with

What Should Disability Service Professionals Understand?

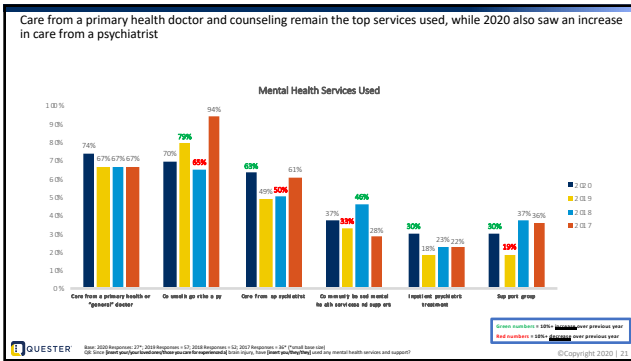
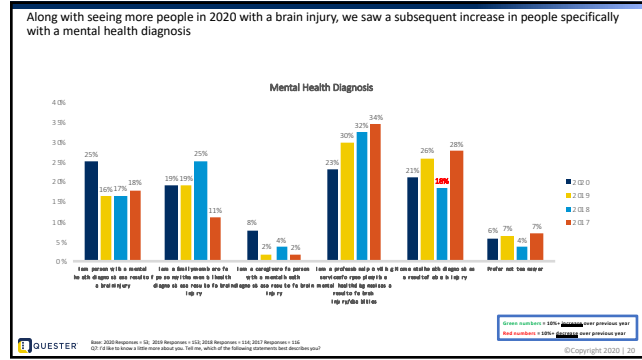
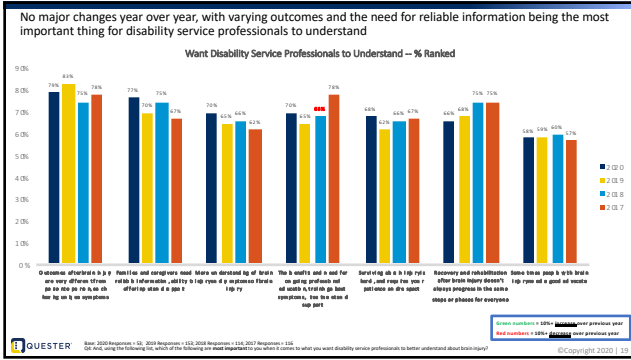
<p>Unique Nature of Injuries</p> <ul style="list-style-type: none"> No two TBIs are alike, and it is necessary to understand the unique nature of each person's needs Additionally, people don't progress at the same rate, and progress isn't always linear - there isn't a standard path, and you need to treat the individualized needs of each patient 	<p>Need Patience, Memory Loss</p> <ul style="list-style-type: none"> Memory loss and cognitive function are key things impacted, and with that comes a need for patience as people struggle to stay on task, focus, remember to do certain activities/tasks, or properly communicate their needs Need some structure, as well as written instructions that are clear and easy to understand 	<p>Can Be Difficult, Emotional</p> <ul style="list-style-type: none"> Emotions change as part of a TBI and it must be remembered that those changes are symptoms of an illness and not necessarily indicative of the patient's personality This is also difficult, and when people feel they're struggling they can get depressed or angry, and even feel the need to yell when they can't get the point across - they are fighting for their health 	<p>An Invisible Injury</p> <ul style="list-style-type: none"> While they may outwardly look completely fine, there is a constant, never-ending internal struggle that is with them every minute of every day Just because it can't be seen doesn't mean it's not there, so it needs to be remembered to have that patience and understanding and not let those feel stigmatized - need a normalization of TBI and to continue to treat patients like people
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Disability Service Professionals Should Understand - In Their Own Words

<p>I would like case managers to understand the process more. Give the clients time to complete their goals before they push them out of a program to sometimes a higher level of care.</p> <p>Brain injuries are not linear and needs may change through the years. Individual may show progress in his rehabilitation and then regress due to medical, physical or other issues. Aging can affect B.I. symptoms. Changes may occur quickly or over time. Each day can be different for a survivor.</p> <p>It's extremely frustrating to us participants also that we have lost our ability to remember what we are doing or what we just said. Use my iPhone and my iPad as my backup brains. I type notes in there so I can look back at my day at nighttime and see what I thought I did or need to do. Trying to stay focused is extremely hard.</p> <p>I guess the main thing for those folks to understand is that for many, most brain injury survivors working memory is pretty much gone. So any instructions for engaging self care need to be told to a caregiver AND written down.</p>	<p>Brain injury individuals can be difficult at times due to the change in their brain. It is part of the illness, not a personality trait. They occasionally have denial with certain things and also blame normal things (i.e. foggy/forgetful in entering a room) on the injury. Understanding their thought process and emotional needs is important.</p> <p>I would like them to understand that brain injury is never ending. I will never recover. This is a permanent condition. I may gain some things back but I will never be 'normal' again.</p> <p>Every brain injury is different. No two people are exactly alike. Thus, each B.I. person may have various needs. There is not a 'how to' textbook to properly respond to each individual's needs.</p> <p>Many times, consumers do not access services due to stigma and embarrassment. I hope that some way we can soften the blow of understanding that having a brain injury is not an embarrassment. It is a way of life and many people have them and really don't understand that they have them.</p>
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Mental health providers need to show compassion and understand that people are going through a tough time and they need patience and an individualized plan that can truly help

This is Tough/Depressing

- Things will never be the same, and that can be very difficult for people to come to grips with
- It often leads to depression – a more “respects” depression
- Providers need to have the compassion and understanding to work with people and understand how difficult it is for them to be going through this
- Help people see what they still do well and strengths that still exist – the same person is still there, it’s just more difficult at times

Need Individualized Help

- Everyone reacts to certain texts or medications differently – need to be able to adapt and adjust to personalized needs
- Can’t treat from a “cookbook” – need to come up with a truly individualized plan to help people get better

Know What They Were Like Before

- Knowing what someone was like before can help providers understand more specific struggles, or what could be a trigger (i.e. someone who was always shy might further struggle in group therapy sessions)

How Medication Works

- Patients need help learning how a medication will work, what the side effects will be, and how it is supposed to make them better
- Need a regular review to ensure medication is working and effective

Behavior Changes

- There can be drastic changes in behavior, from being more agitated and not wanting to discuss anything, to even trying to hurt themselves or others around them

Different Triggers

- Different things set off different triggers – triggers for anxiety and depression are not the same – understand the difference
- What you see in the office may be different than home life – things at home can more easily cause issues

Help Us Not Be Bullied

- Those with mental health diagnoses are often bullied or mistreated – need to see the signs/understand when it’s happening and offer help getting support

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Mental Healthcare Providers Should Understand – In Their Own Words

Assistance with understanding they are who they have always been, but things are different now and there are ways for them to overcome challenges. Helping them with insuring that they may never return to exactly who they used to be, but enabling them to see their strengths and good in them.

My symptoms will vary from minute to minute or month to month depending on internal and external factors. If they could understand that I may have different triggers for my anxiety and depression depending on what is going on at the time.

Facilities need to learn and understand what the person was like before the brain injury occurred. My daughter was very shy and introverted all her life. At both neuro therapy facilities she was in, they put her in with all the other patients in group settings. She was terrified and withdrawn from any possible understanding or help they were trying to provide.

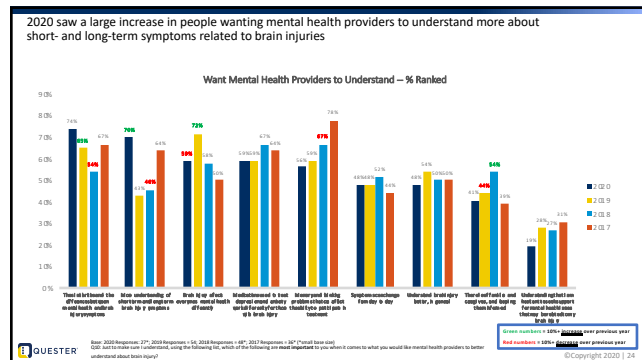
I would love our mental health community and providers to understand that mental health diagnoses can be new for the brain injured survivor. It can be difficult to accept and understand that not only do I have brain injuries but also mental illness from the brain injuries.

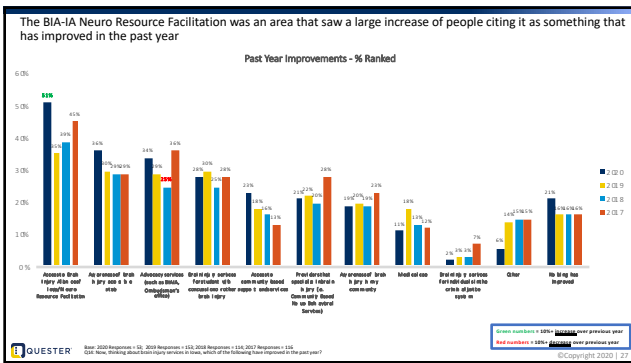
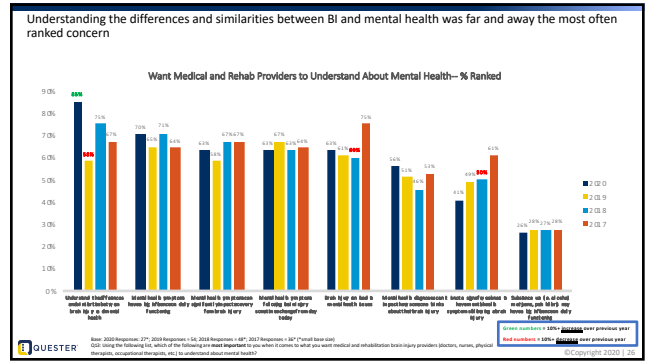
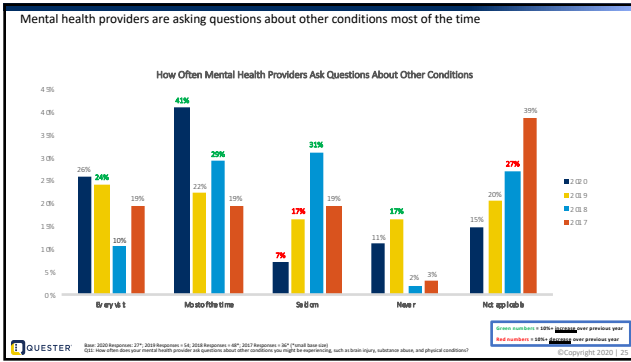
It is extremely frustrating and hard to try your best to return to who you were before your brain injury. For the person everyone knows you as, and not be able to. Depression definitely sets in and that emotion on top of the symptoms of brain injuries is hard. Tears flow frequently even though nothing is newly wrong.

I would like them to understand that medications affect patients with a brain injury different than someone who does not have a brain injury. My son already has huge cognitive issues and certain medications will only make that worse.

I have PTSD, major depressive disorder, and anxiety. But ABOVE ALL I have a TBI. Please don't "cookbook" me along with those who have the same diagnosis without the TBI.

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Some feel like nothing has improved in the last year due to individual struggles with a provider or someone in a position of power

Why Feel Nothing Has Improved?

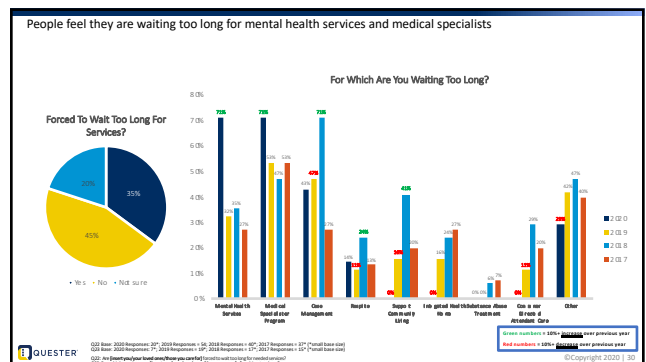
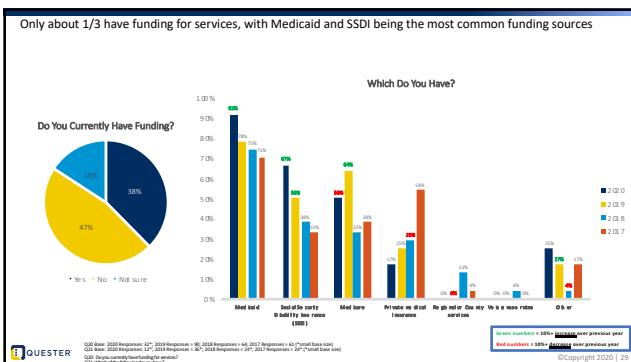
- Often, individual stories such as an early misdiagnosis, have led to treatment being denied, and not getting a referral they needed
- Issues with the Salvation Army and not having the right materials or even accusations of bullying and no justice happening for those doing the bullying
- Feeling that budgets have been cut for some services, so service is not as good
- Managed care makes it hard to access help

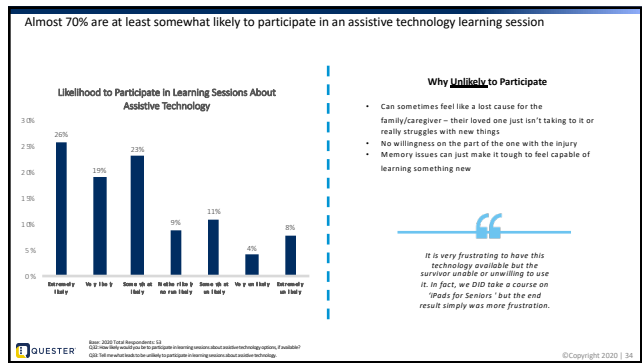
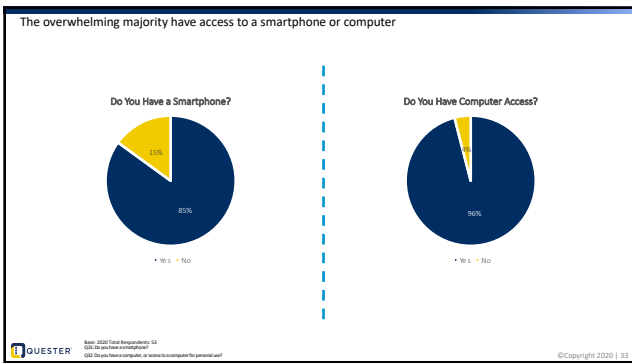
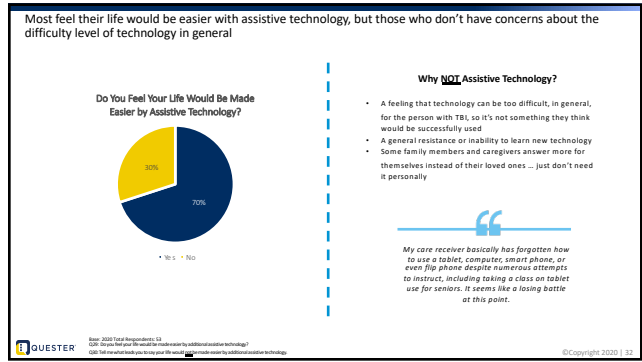
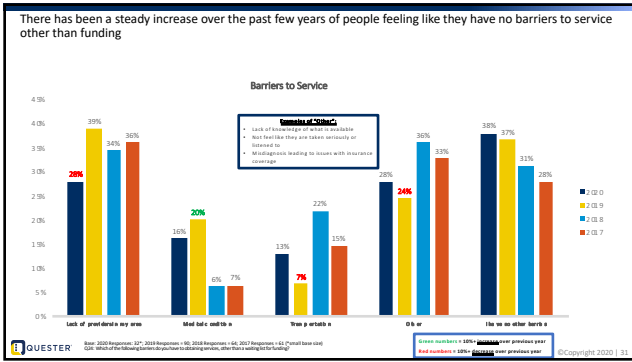
Genesis and its doctors, along with trying Unity Point, has used one sentence by a neurologist who never saw my daughter but only looked at the mandated test performed which admitted to BI, along with test run after being admitted. And very early on the only passed out, but all the tests show normal readings. He said it was 'all in her head' - have been denied treatment within Genesis by a pain management doctor. A referral from Univ of Iowa said don't do second opinions, she has never had a 2nd opinion except for the above so-called doctor. Referral to Mayo Clinic was just denied.

You did nothing with the Salvation Army or my student loan fraud.

I feel that services have been short changed due to budgets being reduced. I feel that some people feel that it does not affect them so they can see cutting the budget because 'those people don't contribute to my political campaign' or 'They don't vote anyway, why worry about them?'

Managed care makes it harder for many to access the needed help for as long as they need it. The pandemic has made everything more difficult.



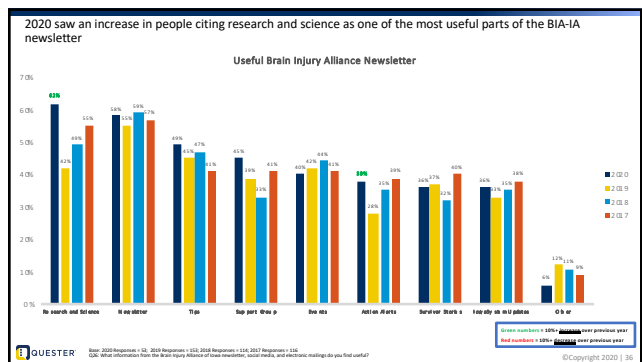


Daily struggles often center around memory loss/confusion, and the everyday Activities of Daily Living

Daily Struggles			
<p>Memory Loss/Confusion</p> <ul style="list-style-type: none"> There can be a general confusion about what is going on A couple specifically mention sundowning as particularly difficult Memory loss makes staying on schedule difficult Can forget where things are in the house, or where something is supposed to go "I've labeled cabinets and drawers but my care receiver still gets confused about where to find things or where to put them away. Sundowning sometimes turning into sunseting is a huge issue." 	<p>ADLs</p> <ul style="list-style-type: none"> Cooking and eating – it can be tough taking the proper size bite Getting dressed Going to the bathroom Personal care "He struggles with most of his daily living skills. He is unable to cook for himself, bathe himself, and even get dressed at times." 	<p>Mobility</p> <ul style="list-style-type: none"> Difficult walking around, getting up stairs Balance – concerns with falls Control of their body/hands "My child struggles to walk around our house and get up the stairs. We have to help with all basic life skills." 	<p>Emotional State</p> <ul style="list-style-type: none"> Emotional state is unpredictable Don't know what's going to trigger an event or how emotions change from one moment to the next "The unknown of what the day will be for the brain injured member. Will it be emotionally charged - anger in most cases? Will it be self pity?"
<p>Fatigue</p> <ul style="list-style-type: none"> Get tired, worn out easily Need regular naps throughout the day "The person I provide services to has difficulties with having the energy to get up to do things. Fatigue is extremely hindering." 	<p>Doing Chores</p> <ul style="list-style-type: none"> Stuff like cleaning the house Doing laundry "I have a chronic daily headache from my concussion. This affects ability for household chores and has affected my relationship with my family." 	<p>Critical Thinking Skills</p> <ul style="list-style-type: none"> Struggle with multi-step processes Inability to stay focused "His struggles are more with critical thinking, multi-step processes, budgeting, organizing, scheduling etc." 	

Base: 2020 Total Respondents: 123
 Q1: How often do you struggle with these activities?
 Q2: How often do you struggle with these activities?

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Additional Thoughts – In Their Own Words

Most don't have any additional thoughts, other than to thank the BIAA for their advocacy and allowing them to share their voice and opinions on the subject
Below is a sampling of additional thoughts that are shared

“The HIPAA laws have gotten in my way in the recent past of my advocating for the personal care for Healthcare providers continue to want to talk only to her – and she will not remember what they say – and not to US. That is changing for the better fortunately.

Our bodies and minds are completely different. My hands and arms are in a constant deep, painful neuropathy that also makes day-to-day living hard.

We are people. We matter. There's a lot of ways for us to be useful and productive citizens in financial ways, but no one has taken the reigns to open up access to these avenues because it's easier to do the least amount of work that's stayed the same for YEARS than it is to create and give the way for us to succeed.

There just needs to be some way for persons with brain injury to find out about BIAA and resources. I know there are TWO couples locally who had not heard of support groups.

I want to reiterate the importance of reversing the privatization of Medicaid. It is imperative toward the quality of living for Iowa's with B.I. and mental health difficulties.

“As a caretaker, I find that support is crucial but not always easy to find. I would like to find more family members dealing with TBI and what works for them.

Motivation is a difficult thing. For some survivors, they're extremely motivated to get back to normal, whatever form normal will take. For others, they do very little to help themselves, despite the several self-help type info available.

People would be better served, the community at large, if they were better educated about brain injuries and some of the effects that it has on people's lives. People think that the only people with brain injuries are the people that have outward effects that you can immediately see and detect. This is a major issue we need to address through education.

I moved here from Alabama. Put yourself on the back, Iowa is light years ahead. BIAA is a godsend. The problem is tucked into BIAA quite by accident while digging on the internet. That should not be the case.

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The sample was 3/4 female, and roughly split on those under 55 vs. 55+

Gender

75% Female, 25% Male

Age

50% Under 35, 33% 35-44, 17% 45-54, 10% 55-64, 5% 65+

* Counties in blue had at least 2 persons complete the survey
** No data for these counties

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APPENDIX: YEAR-OVER-YEAR COMPARISONS

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Sources of Info – Year-Over-Year Comparison

	Total				Person with BI				Family Member			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
Internet	450	480	570	550	130	150	170	180	100	100	100	100
Brain Injury Alliance of Iowa	170	150	150	140	50	50	50	50	50	50	50	50
Health Care provider (or a doctor or nurse)	270	270	270	270	80	80	80	80	80	80	80	80
Reliability Service Providers	700	700	700	700	200	200	200	200	200	200	200	200
Support Groups	700	700	700	700	100	100	100	100	100	100	100	100
BRIDGE	200	200	200	200	50	50	50	50	50	50	50	50
Local media (Newspaper, TV, Radio, Podcast)	100	100	100	100	20	20	20	20	20	20	20	20
La Poudre Health Insurance (PUSH) (BECA, AG)	100	100	100	100	10	10	10	10	10	10	10	10
Family	100	100	100	100	10	10	10	10	10	10	10	10
Workshops/Seminars	100	100	100	100	10	10	10	10	10	10	10	10
Medical	100	100	100	100	10	10	10	10	10	10	10	10
Public Health Department	100	100	100	100	10	10	10	10	10	10	10	10
Employee	100	100	100	100	10	10	10	10	10	10	10	10
Unlabeled Health Care	100	100	100	100	10	10	10	10	10	10	10	10
Neurologist	100	100	100	100	10	10	10	10	10	10	10	10
Advocacy - Managed Care Organization for Iowa Medicaid members	100	100	100	100	10	10	10	10	10	10	10	10
Management/Supervisor	100	100	100	100	10	10	10	10	10	10	10	10
Self / Iowa Medical Extension for Iowa Medicaid Members	100	100	100	100	10	10	10	10	10	10	10	10
Research	100	100	100	100	10	10	10	10	10	10	10	10
Iowa Department of Vocational Rehabilitation	100	100	100	100	10	10	10	10	10	10	10	10
Spouse	100	100	100	100	10	10	10	10	10	10	10	10
Television	100	100	100	100	10	10	10	10	10	10	10	10
Radio	100	100	100	100	10	10	10	10	10	10	10	10
Department of Veterans Affairs	100	100	100	100	10	10	10	10	10	10	10	10
Rehabilitation Center	100	100	100	100	10	10	10	10	10	10	10	10
Medical	100	100	100	100	10	10	10	10	10	10	10	10
Other (not listed)	100	100	100	100	10	10	10	10	10	10	10	10
Total	4300	4300	4300	4300	1200	1200	1200	1200	1200	1200	1200	1200

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Want Community to Understand – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
Brain injury frequently results in challenges and disabilities that others cannot necessarily see	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
Brain injury results from different accidents and scenarios that others overlook	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
After brain injury, the individual may never be the same person they were before	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
Individuals with memory, or language changes can still be intelligent (like regular brain injury)	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
Individuals with memory, or language changes can still function on a very day-to-day basis on any tasks that are not affected by their or another's symptoms	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
People with brain injury can still read, just like they used to	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
People with brain injury can still support and support others	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
My "weakness" is no less in my community the person who is a "stronger" of my community	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
To be more involved in the development of brain injury	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
Brain injury impacts the progress of my	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100
To be more aware about how brain injury can be prevented	400	400	400	400	100	100	100	100	100	100	100	100	100	100	100	100

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Future Improvements – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
Access to medical services for brain injury	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Access to health care services for brain injury	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Insurance (including Medicare, Medicaid, etc.)	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Training and education for professionals	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Programs that specialize in brain injury (or Community Based Mental Health Services)	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Training and education for family members and / or caregivers	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Access to community based support and services	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Awareness of brain injury in my community	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Training and education for providers of brain injury	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Ability to receive services (at work, in the community, etc.)	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Information on living with brain injury	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Brain injury services for individuals in the correctional system	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Brain injury services for individuals with co-occurring brain injury	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Awareness of brain injury across the state	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Medical care	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Access to brain injury resources of Iowa/Neuro Resource Foundation	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70
Other improvements needed	300	300	300	300	70	70	70	70	70	70	70	70	70	70	70	70

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Hardest Part – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
N	53	153	114	110	18	40	25	32	14	50	39	21	63	50	50	50
Financial challenges	154	149	174	155	153	178	175	185	171	145	135	115	173	168	155	155
Memory, language or thinking changes	124	124	124	124	124	124	124	124	124	124	124	124	124	124	124	124
Obstacles to services (waiting lists, transportation, etc.)	47	37	47	47	47	47	47	47	47	47	47	47	47	47	47	47
Changes in ability to work	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Emotional distress	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Meaning to help others	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Ability to complete daily tasks	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Loneliness / Isolation	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Fear of falling, balance issues	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Diagnosis, Resolutions, or other physical conditions	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Transferability to someone for each individual / caregiver's symptoms are unique	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Driving	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Shopping (too little or too much)	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Transportation	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Other challenges than listed	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100

Q1: In your opinion, what are the hardest or most challenging things about brain injury? You may rank up to 6 options.

N = Total number of responses
%BI = Percent of responses from Person with BI
%FM = Percent of responses from Family Member
%CG = Percent of responses from Caregiver

Want Disability Service Professionals to Understand – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
N	53	153	114	110	18	40	25	32	14	50	39	21	63	50	50	50
Disability service professionals are very different from person to person, each having unique symptoms	79%	83%	75%	78%	81%	80%	64%	64%	75%	71%	84%	79%	82%	81%	84%	74%
Families and caregivers need reliable information, ability to offer input and support	77%	70%	70%	67%	67%	60%	64%	50%	60%	50%	67%	67%	60%	67%	67%	69%
Meaning to understand of brain injury and symptoms of brain injury	70%	65%	66%	62%	67%	63%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%
The benefits and need for ongoing professional education, training about symptoms, treatment and support	70%	65%	68%	65%	67%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%
Learning to brain injury is hard, and requires your patience and respect	68%	62%	66%	67%	67%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%
Recovery and rehabilitation after brain injury doesn't always progress in the same steps or phases for everyone	66%	68%	75%	70%	67%	73%	72%	71%	64%	64%	67%	64%	64%	64%	64%	64%
Qualitative people with brain injury need a good advocate	58%	59%	60%	57%	54%	65%	64%	64%	64%	64%	64%	64%	64%	64%	64%	64%

Q1: How, using the following list, would you like to be understood by professionals? You may rank up to 6 items.

N = Total number of responses
%BI = Percent of responses from Person with BI
%FM = Percent of responses from Family Member
%CG = Percent of responses from Caregiver

Past Year Improvements – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
N	53	153	114	110	18	40	25	32	14	50	39	21	63	50	50	50
Access to Brain Injury Alliance of Iowa/Neuroscience Foundation	110	110	110	110	110	110	110	110	110	110	110	110	110	110	110	110
Advocacy services (such as BIAWA, Ombudsman's office)	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Brain injury services for equated with concussion or other brain injury	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Access to community based support and services	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Providers that specialize in brain injury (i.e. Community Based Neuro Behavioral Services)	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Awareness of brain injury in my community	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Medical care	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Brain injury services for individuals in the criminal justice system	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Other	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Nothing has improved	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100

Q1: How, using the following list, would you like to be understood by professionals? You may rank up to 6 items.

N = Total number of responses
%BI = Percent of responses from Person with BI
%FM = Percent of responses from Family Member
%CG = Percent of responses from Caregiver

Useful Brain Injury Alliance Newsletter Information – Year-Over-Year Comparison

	Total				Person with BI				Family Member				Caregiver			
	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017	2020	2019	2018	2017
N	53	153	114	110	18	40	25	32	14	50	39	21	63	50	50	50
Research and Science	62%	62%	49%	55%	64%	60%	51%	54%	64%	64%	51%	54%	64%	64%	51%	54%
Newsletter	58%	55%	59%	57%	57%	55%	51%	51%	57%	57%	51%	51%	57%	57%	51%	51%
Tip	49%	45%	47%	41%	49%	45%	47%	41%	49%	45%	47%	41%	49%	45%	47%	41%
Support Group	45%	39%	32%	41%	45%	45%	34%	35%	45%	45%	34%	35%	45%	45%	34%	35%
Events	40%	42%	46%	41%	40%	42%	46%	41%	40%	42%	46%	41%	40%	42%	46%	41%
Action Alerts	38%	38%	35%	39%	38%	38%	35%	39%	38%	38%	35%	39%	38%	38%	35%	39%
Survivor Stories	30%	37%	32%	40%	30%	37%	32%	40%	30%	37%	32%	40%	30%	37%	32%	40%
News System Updates	36%	33%	35%	38%	36%	33%	35%	38%	36%	33%	35%	38%	36%	33%	35%	38%
Other	6%	12%	11%	9%	6%	12%	11%	9%	6%	12%	11%	9%	6%	12%	11%	9%

Q1: What information from the Brain Injury Alliance of Iowa newsletter, social media, and electronic mail do you find most useful?

N = Total number of responses
%BI = Percent of responses from Person with BI
%FM = Percent of responses from Family Member
%CG = Percent of responses from Caregiver

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