MINNESOTA
Brain Injury Alliance

MIND MATTERS

WINTER 2022-2023

INSIDE—

- Letting Go
- Revisiting Previous Interviewees

... and More

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MINNESOTA Brain Injury Alliance

MISSION

The mission of the Minnesota Brain Injury Alliance is to raise awareness and enhance the quality of life for all people affected by brain injury.

COMMUNITY HEALTH CHARITIES℠

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Chief Executive Officer

Welcome *Mind Matters* readers,

I'm writing this during the first major snowfall of the Winter and it's gotten me thinking about the inevitability of the Minnesota Winter and the cyclical nature of our year. It's always going to snow; the Spring will always arrive; and we'll always be here as sure as there will always be Minnesotans to serve. Brain injury isn't a disease; it can't be stopped with a vaccine or treated with a pill. There's no immunity to it and no one is more or less susceptible based on their genetics.

Brain injury will never go away entirely, no matter how aware we are. No matter how careful we may be. There will always be brain injury as certainly as there will always be another Winter.

So, we prepare. As regularly as we bring in the patio furniture, schedule our boiler maintenance, bleed the radiators and bring the shovels up from the basement, so too does the Minnesota Brain Injury Alliance prepare for new brain injuries. We keep our Resource Facilitators up to date on the newest resources in their areas; we keep our Case Managers educated in the latest developments in services and supports; our ECO team keeps communities alerted to the dangers and signs of brain injury; and our Public Policy squad readied for another round with legislators ensuring the rights of all people living with brain injury. Because, as sure as the snow will fall, brain injury will occur.

And, in the face of such inevitability we must set goals. That's what this issue is all about really, goals. The Minnesota Brain Injury Alliance has a vast set of goals that can be summed up in our mission to raise awareness and enhance the quality of life for all people affected by brain injury. All of our partners and associates have goals: to assist those with brain injury, to discover ways to prevent brain injury, and to recover or help others recover from brain injury.

So, we are here to serve you. Year in and year out, we strive to provide help, hope and a voice for the 100,000 Minnesotans living with brain injury. And, as we do each year, we ask you to help us out.

Please give to the Minnesota Brain Injury Alliance as part of your end-of-year gift giving. We greatly benefit from each and every gift we receive. You help keep us going. You help improve the lives of everyone we touch.

People like Jared Workman and Hannah Wynia, who we're revisiting this issue. People like Kayla Meyer, whose interview you can read on our website braininjurymn.org. And they're just a few of the thousands of people touched by your gifts.

So, visit braininjurymn.org and donate to the Minnesota Brain Injury Alliance. As sure as the snow will fall, we will need your support. So, keep us in your thoughts this season and we'll see you in the spring.

David King, CEO

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Coming to Grips with *Letting Go*

By Mike Strand

It seems to me that one of the common characteristics of brain injury is the number of contradictions it places in my life. The only way I can be a successful person with a traumatic brain injury is to strive against the forces of nature, fate, and the gods themselves. Strive with every fiber and disassociated neuron in my brain. Of course, if I fail, which is usually the case, I'm expected to simply shrug my shoulders and try again tomorrow.

People tell me not to get down, to keep on trying. So now, not only do I fail myself, I fail everybody else. I let down all my caregivers who have placed so much stock in my unconquerable soul.

But, I believe I have found a solution.

Every time I have found myself in a tense situation, say at work, for example. I'm always so busy trying to manage the crisis that I never stand back and say, "Look man, I got a brain injury; cut me some slack! I'm doing my best, and you'll just have to accept that." Instead, I stammer and flood and mumble some apology – and I walk away with my proverbial tail between my legs.

> *"I will forgive myself when I fail"*

I don't like being like that. It is not the path of the spiritual warrior. I need to control those situations, like a master of my fate.

I will control my surroundings by letting go. I will gain control by letting go. I will use a contradiction as a tool. It's about time!

I have been trying to master my world by controlling it, just like I did before my accident. It is time to stop trying to control things that I have no power to control.

This starts with not worrying. If I always do my best (and my best is different every day), then I have done everything I can do. If it is not enough, then there is nothing to fret about. Yes, I can imagine a person doing the job better, but I am no longer that person.

A friend is arriving tonight on a 10 p.m. flight. I would like to be someone who can go pick him up, but I am not that person. I used to kick myself and be disgusted with the situation. It changed nothing. I will have to see my friend another time or have him stop by. Maybe I can help him arrange another ride, but I cannot go get him myself.

If I were ten years old, no one would expect me to drive him home from the airport. That is the way it feels when I tell someone I can't do something that they probably didn't think twice about asking me to do. I feel like a kid again, and not in a good way! This makes it hard, but it doesn't make it any more possible.

I must shrug the weight of the world off my shoulders and choose loads I can manage. I must choose things I can control. I say "choose," because it isn't a matter of black and white. That is the hardest part. Maybe I can do it with no problem. Many times, that has seemed the answer, but then I look back on it after a calamity and wonder, what was I thinking?

I will err on the side of forgiveness. I will do my best, and I will forgive myself when I fail.

Revisiting The Workmans

By Phil Gonzales, Public Awareness Associate

I met Audrey and Jared Workman five years ago in 2017 when I visited them at their apartment in Minneapolis. Jared had been bucked from a horse in 2015, spent a month in a coma and still managed to marry Audrey the following year. They'd been living as students in the Twin Cities, far from their families, learning to adjust to Jared's needs as they grew together as a couple. At the end of our conversation, they both expressed a goal to move into a house and start a family. Jared wanted to get back into the working world and Audrey had the goal of letting Jared take on a more active role in running their household.

I'd run into both of them at a Walk for Thought a few years ago. They'd surprised me then with the addition of a baby to their entourage. Little Izzy was a sign that they were working to meet the goals they'd set. I was looking forward to running into them at future events.

Then COVID hit and we didn't see one another for a long time.

Sitting in their house in 2022, I'm a bit overwhelmed by the size of the living room and the chaos of their now two children. Little Lily is a year old and Izzy is happily running all over the place, assailing me with questions about my age, my interests and whether or not I've gone on the Big Blue Slide.

"He's not big enough for the Big Blue Slide yet," Audrey explains. "Right now he's obsessed with slides but a few months ago it was car washes. I have every YouTube video of a carwash out there."

Happily settled in a sprawling house in Otsego, the Workman family is noisy and rambunctious. Audrey sits on the couch, ready to fill me in on their recent history. Jared sits in his wheelchair, his voice rarely raised above a whisper, and tosses in smart aleck comments from time to time.

They are the same couple I met five years back, but more centered. They seem more sure of what they're doing and a little less frightened about the future. And, they've found a place with a great community and a lot of supports.

"We've made a lot of long lasting friendships and connections," Audrey says, "and we love the people here. We think it's a great place to raise our family. And a major part of it, as well, is the support we can get for Jared.

With Audrey's family still in Utah and Jared's in Florida, I wonder how it works being so separated from that source of support.

"I think it's important to maintain family relationships," says Audrey, "but we can be independent out here. And, we're not always relying on them to just help us with our needs and we can just have a more normal relationship, if that makes sense. But, we're still trying to convince family to move out here."

With their home set up and their support network in place, Jared has been able to get back into the working world as a freelance web designer. Even though the nature of freelance work means it's a little less reliable some weeks, being able to contribute to the family income has done wonders for Jared's self-esteem. Audrey works remotely doing healthcare analytics, so they're both able to be home for the kids each day, wrangling meals, diaper changes and showering their kids with affection as a couple.

Jared appreciates the bigger house and the extra space it affords his family.

"I like it a lot more," he says. "But, it's a further drive."

"Oh, yeah," Audrey says. "Hospital visits, appointments and stuff. But I'd say we have been at a steady place with a lot of Jared's care needs, for the most part. And we've been able to just focus on parenting our kids and so that's more where our thought and energy goes."

Although Jared's medical needs have leveled out, he still has a PCA who comes every day to help him. This led to a rough December last year when their PCA was ill and they hadn't secured a nanny yet for the kids.

"So, yeah, we've had some challenging times," Audrey recalls.

With the household Jared and Audrey run, how do they find a balance in their lives between work and family; How do they manage to separate the two? Or, with Jared's PCA, the three: work, family and recovery.

"It's difficult," Jared says.

"Yeah, sometimes," Audrey agrees. "But, I'd much rather it be this way than commuting and being away from all these guys. So, there's pros and cons. But, COVID blessed us in some ways. I didn't think I could be a remote employee before."

Looking at the Workman family, I'm amazed at how much they've accomplished and how they've realized so many of the goals they'd laid out five years ago. The house, the kids, the jobs, the community: it's not only something to be amazed by; it's something to be proud of. And, it's something they both take a lot of pride in.

"My family and all my friends," Jared says in response to what he's most proud of.

"And we want our family to keep growing and growing," Audrey says, "And to just enjoy the years while they're young and learning and growing."

I didn't intend to frame Jared and Audrey's goals from 2017 as some sort of five-year plan, but it happily seems to have turned out that way. Their ideas were challenging, they knew that from the beginning, but also realistic. It hasn't always been an easy road, but with the support of their community and their unwavering love for each other, Jared and Audrey have a great chance of realizing their goals for the next five years as well.

I just hope I get to talk to them before then.

Accomplishing Goals Through Limits

By Phil Gonzales, Public Awareness Associate

Hannah Wynia had definite goals when I first interviewed her and her sisters Mary and Ally back in 2018. She was studying to start a career in social work and eager to move on from the brain injury she'd received in a horse riding accident three years previous. She also was acting as her sisters' guide through their own brain injuries, trying to keep them safe and helping them learn to be self-advocates.

"I remember things were very chaotic back then," Hannah tells me over Zoom. We're chatting in between some of her rare downtime between work, grad school and planning for a wedding that is only a month off. "I still didn't really have everything figured out health wise, like how to get through classes. And my sisters were still kind of having a tough time with their concussions. Theirs were pretty recent, mine was more in the past at that point. But, honestly, now everything's going, like, great. I kind of figured everything out."

Figuring things out took time. Hannah struggled with reading comprehension in school and still doesn't consider it her strong suit. But, she grew accustomed to asking her instructors for the accommodations she needed and learned to adjust to her new situations. She also went straight from getting her undergraduate degree in social work to St. Thomas to pursue her Masters.

"I'm an LSW (Licensed Social Worker) right now," she says. "But I'll be able to get my LGSW (Licensed Graduate Social Worker) in the Summer, which means I can actually work more with people that have mental health problems and more medical issues. I like learning and I feel like I got cheated out of a lot of school so I kind of just keep going. And, I'm actually going to be graduating in May."

In addition to her job as a social worker and her graduate studies, Hannah is a homeowner with her fiancee – now husband Ethan – and the two of them began fostering dogs in January 2021.

"We've had twenty-five dogs and we still have one; he's kind of a long term foster. And then we have our own dogs. So, yeah, our house is kind of a madhouse."

If this seems like a lot to focus on, Hannah is quick to point out that multitasking is a skill she had before her brain injury and one she worked very hard to reacquire.

"My doctors said I might not be able to multitask again. But, I was very persistent," she explains. "I want to be able to do school and have a job. It's definitely not the easiest thing in the world, but I like it. It makes me feel closer to how I was before the accident."

Hannah presents as extremely together and unflappable. However, she's honest about the toll things like extensive screen-time take on her. Her concentration isn't what it once was and she gets easily overwhelmed by auditory stimuli. She and her family also discovered that her memories from before the accident are full of gaps and that many of the things

> *Back then it was just trying to get through day-by-day, class after class. Because each class was hard, especially if they're in-person, because I didn't understand why I was having such a hard time. Because, I didn't used to have a hard time with it. So, 'Why can't I do it now? It's been how many years? I should be better.' But now it's kind of like, 'Okay, this is just how things are. And it's fine.'*

she thinks she remembers from her past are filled in with artificial events.

"It's gotten to where they'll just say, 'Oh, that's just one of Hannah's memories!'"

One of the lasting effects of Hannah's brain injury was chronic pain, which used to be persistent and unyielding to the point of her missing school. Through mindfulness and relaxation techniques, Hannah has learned to control it. She had been told to expect to return to the pain clinic eventually and, much to her surprise, she hasn't had to.

"I do have limits," she reminds me. "And I had to accept that my limits may be earlier than some other

people's, but that's fine, because everyone will have the things they're not great at."

Hannah's attitude and her approach to achieving her goals require a lot of reflection and understanding her limits. Her brain injury isn't something she dwells on, but it's not something she shies away from discussing.

"It's funny when I tell people that I have a brain injury and they're all, 'Really?' I hide it pretty well. But, there are moments like, once I point it out, they can go, 'Okay, I can, like, see what you mean.' But most people don't know. I don't even disclose it, sometimes, at jobs because it doesn't affect everything. And, if it does, I've learned to accommodate and they will really never have to know unless something comes up."

Ally and Mary, who were so rambunctious in our original interview, are both doing very well. Ally is in nursing school in Rochester which Hannah considers a huge deal as they once feared she might not be able to get through high school because of her concussions. Mary is learning to drive and avoiding hitting her head on any more church doors. Hannah still reminds them to keep on top of appointments and plays a bit of the mother hen to them, but things are going really well for the Wynia sisters.

Hannah's life has gone through a lot of changes over the last few years. She's accomplished so many of her goals in spite of the challenges brain injury has thrown in her way. Reflecting on how far she's come, Hannah admits it was tempting to put it all behind her.

"I think I still had some anger back when we last talked," she says. "The 'why me' kind of stuff. But now it's fine. I mean, I did debate whether or not to do the interview, because I was like, 'Oh, do I want to kind of dredge this all up again?' But then I was like, well, I like advocating for brain injuries and making people know that it's sometimes hidden. So I was like, okay, I'll do it. And then I also got asked to talk at my old school, university again, which I haven't been able to do for a while. So we're gonna do that and get back into all the advocating stuff, which I like.

"I've had a tough time, but other people have had a tough time too. You can't go back and change it. So just focus on what you can do now to make everything else better going forward. And I guess I threw myself into helping others and helping animals, which I like. I feel like I've come a long way. I guess it's maybe a little bit of rebellion from everything they said I couldn't do. I was like, 'Okay, nope.' I think my parents made me work very hard to get to a new normal, to not dwelling. So I don't, I don't dwell."

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If you believe in a Minnesota where everyone recognizes brain injury and its effects; where all individuals living with brain injury are encouraged to realize their full potential; and where the greater community recognizes the intrinsic value of all people living with a TBI, we hope you will give to the Minnesota Brain Injury Alliance today.

Over the past three years, the MNBIA has expanded its reach by offering online options for many of its services. Our teams worked hard to make sure that Minnesotans had access to opportunities and supports whether they were in our offices or at home.

Thank you for your commitment to the Minnesota Brain Injury Alliance and for your continued support!

We would like to make sure these opportunities remain available across Minnesota and, to help ensure that, we need **you** more than we ever have before.

Please donate to the Minnesota Brain Injury Alliance today. A gift of $50, $100, $250, or whatever is meaningful to you, can help us continue to offer educational opportunities, advocacy training, and volunteer training. YOU make a difference when you include us in your gift giving. Please, donate online at braininjurymn.org/donate.

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Public Policy

By Jeff Nachbar, Public Policy Manager &
Katrina Meyer, Public Relations Associate

Medicaid Matters

For anybody who is facing long-term impacts from a brain injury there can be no more important government program than Medicaid. Also known as Medical Assistance or MA in Minnesota, this program can assist people with their recovery and provide the services and supports they need to lead a life that is as independent and successful as possible. Not only can MA provide traditional healthcare benefits, it can also provide home and community-based services designed to help people live independently in the community and stay out of costly hospitals or other institutions.

These home and community-based services are commonly provided under the term or program known as "waivers." This simply means the state must apply for a waiver from Medicaid in order to pay for these services under the state MA plan. You've probably heard of the brain injury waiver, the CADI waiver or the DD waiver but, like most people, you might not understand how they work. However, it really is worth it to try and understand these critical services and supports because they can make such a huge difference in the quality of people's lives.

What is Medicaid? How does it work? What does it pay for? Who gets it?

Medicaid is a partnership between the State and Federal Governments to pay for healthcare for low income single adults; low income families with children; and low income elderly and disabled individuals. In Minnesota our Medical Assistance or MA program is matched by the Federal Government through Medicaid dollar-for-dollar. Meaning, if approved by Medicaid, for every dollar the state spends on MA we get an additional Federal dollar for the program. It allows the State to purchase two dollars of services for every dollar spent, essentially doubling the impact.

There are three qualification categories or "doors" through which a person or persons can access MA. As mentioned above, they are single adults; families; or elderly and disabled. Each of the three have their own different qualifying standards, requirements for participation and lists of services they provide. For example, home and community-based services (HCBS) or waivers can only be accessed through the elderly and disabled category. You need to be "certified" as disabled to come in this "door" and it has the strictest income and asset standards. Single adults who are not "certified" as disabled can only get healthcare services and do not get any home or community services.

All MA programs require ongoing eligibility verification and tons of confusing paperwork. There is even a Department of Human Services term for this: "Churn." Churn refers to people going on and off benefits, not because they don't qualify, but because their paperwork is missing or wrong. Also, the rates that MA pays providers is very low making finding service providers difficult. There has been a long-term ongoing staffing crisis, predating the pandemic, for providers to find enough workers to meet people's needs.

This is only a brief summary, but next time you hear things like "We need to get CMS approval for our waiver amendments" or "You have to pay a spend-down to qualify for an Independent Living Skills worker?" or you wonder "Why could I lose my waiver if I have more than $3,000 in the bank?" you'll have a bit of a framework for understanding. There are many other twists and turns, exceptions and alternatives, so please let us know if you have specific questions that apply to your situation.

There is much to be done and the Minnesota Brain Injury Alliance is committed to improving Medical Assistance in Minnesota and asks you to join with us in supporting changes to make it work better and be more sustainable into the future. Please contact Jeff Nachbar or Cynthia Callais to get involved.

Working Together to Reach Recovery Goals

Life after brain injury is full of challenges and like many difficult tasks in life, achievements in brain injury recovery are best accomplished with a team of supporters helping you overcome the obstacles on your path. No two brain injuries are the same so each recovery process is unique with its own support issues and needs. The Minnesota Brain Injury Alliance's Resource Facilitation Program understands this and helps each participant set and meet their own personal goals on their unique recovery journey.

Much of Resource Facilitation's work is listening to each person's story and helping participants work towards their own unique recovery goals. Sometimes this involved helping people find the right healthcare provider; explaining how a complicated government system works; or providing encouragement to not give up. Regardless of how someone got here, the most impactful service that Resource Facilitation provides in helping people meet their recovery goals. The ability to connect and understand a person's experience with brain injury validates their experience and helps them move forward on a personal recovery journey. This is what Resource Facilitation is all about.

If you are looking for this type of support, reach out to Resource Facilitation at 612-378-2742 or 800-669-6442. If you are a service provider and you would like to know more about how to connect people with Resource Facilitation, contact Katrina Meyer at katrinam@braininjurymn.org or 612-238-3241. Let's work together towards reaching these recovery goals!

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Setting and Achieving Goals

While many people are good at setting goals, few of us are able to easily achieve them. Nonetheless, goals are important because they help us move forward in life, turning hopes and dreams into possibilities and those possibilities into reality.

Because inspiration doesn't often come when we are thinking about our goals – more often, it comes when we are not focused on them – setting goals can be difficult. Like keeping track of dreams at night that evaporate in the time it takes us to open our eyes, goals must be immediately captured in writing or electronically so that they stay with us. The simple act of capturing a goal will allow it to incubate in our brain into new insights and a fresh perspective without even knowing it.

Once we have set several goals it's time to prioritize. Do we start with the easiest, fastest, most important, or the one with the biggest payoff? How we prioritize is up to us.

Now, how to make our goals happen? Goals are hard to achieve when we go it alone. Having someone to share your plan and progress is one of the best ways to improve the chances of staying motivated through the barriers and hurdles that will block your progress. One way of looking at motivation is the percentage chance that we have of sustaining our efforts to change at any point in time. It's difficult to sustain that effort and important to realize that motivation fluctuates. We need to give ourselves grace at the dips and slips. It's important to share our efforts with another person because they can help us find that grace when we can't seem to muster it for ourselves and they help us carry on from one slip to another until we can achieve our goals.

— by Dr. Erwin Concepcion, MD

Setting goals after a brain injury can be an important part of recovery. However, it's important to set realistic goals to avoid feeling frustrated if you're not reaching them quickly enough.

For example, let's say your goal is to get back to work (40 hours a week). While this may seem like a reasonable goal, it may not be realistic to actually get back to 40 hours right away; your brain and body simply might not be ready for it. It is likely going to take some time to work up to that 40 hour week. So instead, consider a goal of volunteering for five to ten hours a week (maybe at a local animal shelter, or whatever feels good to you).

You may find that five to ten hours is simply exhausting, or it may feel incredibly rewarding. The key here is to truly pay attention to how you feel, and see if you're able to push yourself further or not.

It's all about baby steps. Starting small and working your way towards your larger goal will feel a lot less overwhelming, and will relieve some of the frustrations you may incur if you try to jump to your big goal right away.

Believe me, I completely understand the frustrations of not being able to do what you did before your injury. There is nothing more annoying than hitting obstacles every time you seem to turn a corner in your recovery. Being realistic about your goals is one way to give yourself some control of the situation, while feeling good about achieving those baby steps along the way.

What goals are YOU going to set for yourself this month?

—Amy Zellmer

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