





THE PATH AHEAD

Volume 8, Issue 1



tmgwisconsin.com

Keep up to date with TMG!

TMG has created a brand new library of Frequently Asked Questions to help you better understand some of the news, regulations and processes in Wisconsin's self-directed long-term care programs, including IRIS and SDPC.

You can find these new documents by clicking on "TMG News & Notes" on our website homepage: **tmgwisconsin.com**.

To help you stay up to date between visits to the TMG website, we've also created an easy sign-up system so you can receive **email alerts** when new or updated information becomes available.

Your family, caregivers, friends and supports are also welcome to sign up for these emails. That way, you can stay up to date together.

Just visit **tmgwisconsin.com** and click the "Emails and Alerts" button at the bottom of the homepage to sign up in just a few seconds!

Upcoming Events of Interest

- APRIL 21-22
 Circles of Life
 Waukesha
 www.circlesoflifeconference.com
- APRIL 29-30
 NAMI Wisconsin Annual
 Conference
 Elkhart Lake
 www.namiwisconsin.org
- MAY 1-3
 Alzheimer's Association
 Annual Network Conference
 Wisconsin Dells Kalahari
 www.alzwi.org
- MAY 5-6
 Circles of Life
 Wisconsin Dells Wilderness Resort
 www.rfw.org

Stacy Ellingen



30-year-old Stacy has never met an obstacle she couldn't overcome. As a child growing up with cerebral palsy, Stacy learned quickly that she could achieve anything with the right attitude and supports.

"Despite having severe physical limitations, I was brought up believing that I should/could do everything that everyone else does," said Stacy. "My parents did a great job of treating me no differently."

It's her determined spirit and support from her family that has led her to seek independence in all aspects of life. After graduating high school, Stacy left home to study Journalism

and Advertising at University of Wisconsin - Whitewater.

"Going away to college was a huge milestone in my life," said Stacy.

"Beyond getting a degree, it proved to myself and others that with
the right supports I could live independently."

After college, Stacy was determined to continue to live independently but struggled to find the right place in her hometown. After researching different options, Stacy found a home in Oshkosh with supports from Cerebral Palsy of Mideast Wisconsin. "February marks five years I've been living independently!" said Stacy.

Throughout that time, Stacy worked closely with her TMG IRIS Consultant. "Kathi has helped me reach my goals in many, many ways," commented Stacy. "From helping me find resources when I first moved to Oshkosh, to being part of my employment team and supporting me through that whole process. She has been amazing!"

Stacy now leads a busy professional life as a small business owner and an independent contractor with InControl Wisconsin, an organization that plays a key role in advancing self-directed supports in Wisconsin. "I love working for InControl Wisconsin because I feel like I'm helping people," said Stacy. "When you need as much help from others as I do, you often feel like you can't give back enough. Working for a disability advocacy organization makes me feel like I'm helping others—it gives me a purpose in life!"

Her work at InControl Wisconsin has inspired Stacy to become more involved in disability advocacy efforts and the community at large.

For Stacy, support from TMG and the IRIS program has made pursuing her passions and her journey towards independence much more possible. "IRIS has helped me achieve two of my biggest goals in life—living independently and gaining employment," said Stacy. "I had huge hurdles to overcome and there were many bumps in the road, but with the support of TMG, IRIS and others, I was able to achieve my goals!"

Henry Henning



Growing up in the small town of Elk Mound, Wisconsin, 20-year-old Henry has been an important part of his close-knit, high school community. Henry has Down syndrome, and has had a fully inclusive school experience, sharing the same classroom experiences as students without disabilities.

"I felt that it was important that Henry had the opportunity to interact with the other kids," said his mother, Janet. "Henry is extremely social and he loves his classmates."

However, when school lets out for summer vacation, Janet and her family have struggled to offer the same socialization and structure for Henry.

"We live out in the country," said Janet. "We can't leave him alone all day by himself. There's unforeseen things that can happen and we want him to be safe."

Henry is often independent, but Janet explained that he is still at risk. "He sees people from a different perspective – in such a positive light," said Janet. "It's the beauty of Down syndrome but we don't want a stranger to take advantage of that."

Fortunately, Henry's TMG IRIS Consultant, Nicole, has helped Henry direct his IRIS funds to not only get transportation, but to hire trusted direct support people to spend time with Henry during the summer. "They go for walks around town or they take him to the YMCA." said Janet. "His favorite thing to do with them is volunteer at the Bethesda Thrift Shop."

Janet explained that if it weren't for the IRIS program, Henry wouldn't have had the same opportunities. "I'm so thankful we have IRIS - I don't know what we'd do without that support," said Janet. "One of us would have to quit our job or work nights so that someone could be with him."

As a Project SEARCH participant, Henry is currently working toward graduating and finding employment. "Through Project SEARCH, Henry has been exposed to different jobs," said Janet. "We've discovered that he really enjoys organizing and sorting things." Project SEARCH is a collaboration with local businesses that enables young adults with disabilities to gain and maintain employment through training and career exploration. All participants must be eligible for services with the Wisconsin Division of Vocational Rehabilitation (DVR).

Henry, like many people, can find conversations in new relationships difficult. His Project SEARCH teacher has helped him find different ways to share his thoughts and goals with others at work.

"He loves to make PowerPoints, so when he's having a hard time verbalizing things she asks him to put it in a PowerPoint," said Janet. "He can't always get the words out but he can put it down on paper – it's amazing how his mind works that way!"

Janet and Henry are searching for a position after graduation that both uses his skills and that he enjoys. "In the meantime, we want to keep him active and engaged in the community so that he can continue to grow," said Janet. "I'm so thankful and relieved that we have support from Nicole and IRIS so that we can do that."

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Amanda Alcala



For Amanda and her family, coordinating care can be a challenge. In fact, it's often their family's main focus.

Amanda was born with cerebral palsy and has spent much of her life in and out of hospitals. "In the middle of elementary school, she started having really bad seizures," commented Amanda's mother, Irma. "In high school she needed multiple surgeries and

eventually had titanium rods put into her back to keep her sitting straighter."

Throughout her life, Irma has been Amanda's number one advocate and care provider. "Amanda has many disabilities which makes it challenging," said Irma, "But as a parent, I know what kind of care she needs."

When Irma first learned about TMG and the IRIS program, she had a positive response to self-direction. "Amanda's care is so day-to-day that we need to know exactly what care she will receive and we need to make those decisions ourselves," said Irma.

Soon after, Amanda enrolled in IRIS and first met her TMG IRIS Consultant, Melanie. "Right away I thought, 'I love this lady," said Irma. "I felt a connection with Melanie and I could tell Amanda did too, she is so caring and understanding."

In the last several years, Amanda has experienced many challenges. "Amanda has a hard time sleeping, she has stayed awake for 10 days straight and has been fully asleep for eight days straight." It can be extremely taxing on Amanda's health as well as her family. "She needs a lot more care now than what she used to."

With Melanie's help, Amanda's family has been able to rally around her with a network of supports. "Our whole family is listed as supports," said Irma. "It's important to have someone we trust come over and take care of her while we do errands or get some rest."

Melanie also works hard to provide much needed emotional support to Amanda and her family, "If Amanda was in the hospital, I'd call Melanie right away," said Irma. "She would take care of everything and then call back to check in on us. She really cares."

At age 21, Amanda is now completely transitioned out of high school and receives supports from Lakeside Curative Care in Racine. "Amanda has a lot of friends there and really loves going," said Irma. "She gets to do music therapy, spend time in the greenhouse, cook and hang out with other friends."

As Amanda looks to her future, her biggest focus is her health. "The number one goal right now is to get better - her health is the priority." Amanda's mother takes comfort knowing that Melanie will be there to help Amanda and her family work toward that goal.

"Every parent wants to know that someone is there to help - we need that," said Irma. "Melanie is always there, doing her best to help us."

Share Your Story



The best part about *The Path*Ahead is the stories from people who show how self-direction works for them every day in creating their best possible life. Would you like to share your IRIS experience with others in the program?

Talk to your IRIS Consultant, or visittmgwisconsin.com and click on "Share Your Story" at the bottom of the homepage. You might be featured in an upcoming issue of *The Path Ahead!*





Your goals are in **FRONT OF YOU.**



IRIS is **BEHIND YOU.**And TMG is **BY YOUR SIDE.**



Together, Let's Clear the Path Ahead.

From the TMG Mailbag...

The Department of Health Services 40-Hour Health and Safety Assurance Policy

Question:

I've heard about a new 40 Hour per week limit for my workers. Can you explain?

Answer:

In short, the Wisconsin Department of Health Services (DHS) wants to make sure that participant hired workers are providing high quality, safe care to people, and are not working so many hours that they become burnt out or over-tired.

DHS has released a policy and work instructions that create a 40-hour per week work limit for each participant hired worker. There may be exceptions granted for individual workers to provide up to 50 hours of care per week. People with workers who are currently providing more than 40 hours of support per week will have a transition period ending December 31, 2016 to find additional workers, hire agencies, or make other arrangements to ensure their plans align with the policy.

You can connect with your TMG IRIS Consultant to learn if this change will impact you and what steps you might take to continue on the path to meet your goals.

See page two for sign-up instructions if you'd like to receive email alerts when other important information that might affect you becomes available.

*This FAQ is based on information that was available from the Department of Health Services on March 18, 2016.



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