

touchstone

A quarterly publication providing the latest news & information for individuals with disabilities, families, friends and our community.

My Autism: A Day in My Life

By ERIN MCKINNEY

The alarm goes off right when it's supposed to. I hit the snooze one time, then it's time to get up. I complete my morning routine. It's the easiest part of my day. Always the same, never changes. It gives me comfort. Take care of my dog, then take care of myself. Check the weather first, then get ready. Meds. Don't forget those. Double-check my backpack. Check the stove, check the locks, check the lights, check them again. I know they're just obsessive thoughts, but I have to satisfy them. Finally time to go. Right on time.

The sensory onslaught starts as soon as I walk out the door. On this day, the wind whips, the rain pounds, and the thunder roars. I head to the car where I sit for a minute and gather my focus before I put the car in reverse. The nerves have already shown up for the day and I haven't even left the parking lot. It takes every ounce of focus to get to Chick-fil-A. It is Friday, which means I treat myself to breakfast out. I spit out my order at the drive-through. My phone's already buzzing for work. By the time I get to the window, I've lost my words. I fumble for my debit card. She asks how I am. I can't respond. She asks if everything is OK. I nod my head. Inside, I'm apologizing profusely. It's not unusual for me to lose my words. They get scrambled in my head and I can't get them out of my mouth. It never gets any easier to get out of the situation despite how often it occurs. I finish my drive to work replaying what just happened.

By the time I get to work, I have to shut the door to my office for a few minutes. I grab a chew toy out of my fidget box and spin in my

chair. I could do that all day. Instead, I check my to-do list and update it using my blue pen. It's the last of its kind and won't last much longer. What will I write with when it runs out? It's an anxious thought. I'm learning about those in therapy. What am I supposed to do next? Look for evidence that supports it, then look for evidence against it and come up with a new thought. It's loud in the office. The lights and the computer buzz. I try to push the noises aside and find my focus. It's hard today. I don't know why. Did I do something wrong? Another anxious thought. What's first on my list? I get started preparing for an upcoming opponent (I get paid to watch basketball for a living).

I have a question but I really don't want to talk to anyone. What if I mess it up? I have to ask, though. I prepare the conversation in my head: what will I say, what might they say in return, what's my response. Oh yeah. Don't forget to look up. I don't have to look at his eyes, just pretend. Try to focus on something behind his face. It will make him think I'm looking at him, which I'm supposed to do but just can't. I can't look and listen at the same time. It hurts. No unexpected behaviors when I leave my office. That means no snapping, no flapping, no rocking. Just walk down the hall, follow the script then walk back. Say a quick prayer that no one stops me. If they do, just say, "Good morning."

I grab a bouncy ball and head down the hall. I make it unscathed, though my



ERIN MCKINNEY

heart rate would tell you otherwise. The door's closed. Do I open it, knock, or turn around? Which one is right? Nothing comes easy. I elect to knock and he motions for me to come in... I think. "Good morning... I'm good. How are you?... I have a question..." Come on E. Spit it out. You can do it. I manage to ask my question. He responds with a multi-step answer. Shoot. I can never remember multiple steps. He keeps going. Focus E. First, then, after. He's finished. "Thanks." I repeat it to myself as I walk back towards my office. I cross my fingers that no one says anything or needs anything as I walk down the hall. It doesn't work.

"Hey E. Can you come here?" **Uh oh. Unexpected event.** "What's up?" I respond. That seems to be a standard response illustrating my desire to listen. I use it often in the office. I think it's safe. I guess I'm not really sure. She just has a quick question. I can help. It feels good to help. She likes to use smelly lotion. I guess she likes it. I don't. Focus E. Fix it and leave. "You're welcome." I continue down the hall. I make it back to my office after what seems like an eternity. My heart is racing. It will slow down eventually. How did that go? I made it. I got the information I needed, although I'm not sure I remember all of it. The conversations replay in my head. Did I do it right? Did I make them uncomfortable? Did I rock or did I stand still? I'll never know.

I'm exhausted. It's not even lunchtime. I grab my chew toy and get back to work. It's going to be a long day.

McKinney is a video coordinator for the IU women's basketball team and has autism.

Planning for the future at Stone Belt

Although our crystal ball is rather murky at times due to pending government policies, funding changes and societal shifts, we do our best to shape our own destiny and to respond to changing landscapes over which we have little control. To this end, a good deal of our energy lately has been focused on various planning activities.

Strategic Plan

Every three years, Stone Belt's board of directors and senior leaders develop a strategic plan. It is based on input from many different sources, including client, family and staff feedback, agency performance and factors in the external business environment. We spend about six months working on the plan before it is adopted by the board of directors.



LESLIE GREEN

Our new plan was adopted in July. It will be in place for fiscal years 2019 to 2021 and will guide our initiatives during this time. The plan is focused on improving quality of life outcomes for those we serve. Leadership has been working to develop outcome measures that will help gauge the amount of choice people have in their lives, if they are developing personal capabilities, the degree to which personal relationship and inclusion positively impact their lives, and if they feel they have purpose and meaning in their lives. These are tall orders, for sure, but our efforts will be focused in these directions. A copy of the Strategic Plan can be found on our website at www.stonebelt.org.

A key part of the plan is to develop an

effective **performance management system**. Evaluating how we are doing will require input from all parts of Stone Belt, including clients, staff, families and constituents. This will help us gauge the quality of services and client outcomes on a continual basis. We plan to gather feedback in shorter and more frequent pulse surveys, rather than sending longer annual surveys. This will permit us to respond more effectively and quickly as input is obtained.

Legislative advocacy will also be important to the success of carrying out the plan. We are adding some new activities to engage all constituents in these efforts. One example is the Advocacy Lunch Series that begins on October 25 with a talk by former Indiana Senator Vi Simpson. She will be discussing how individuals can effectively educate legislators and how to become more engaged. This meeting will begin at 11:45 a.m. at our Adams Street office, located at 550 South Adams St. Anyone interested is invited. There will be two more sessions in the series, including a January 24, 2019, presentation from Kim Dodson, executive director of The Arc of Indiana. Watch our social media and website for more details.

One thing is for sure: We will continue to advocate for increased funding that will allow us to better pay our staff. We have made some progress in raising salaries, especially of direct support professionals, but it hasn't been enough to attract and keep sufficient numbers of staff. We hope you will be active in our advocacy effort as we encourage the Indiana General Assembly to increase funding. We need to close the staff vacancy gap, better reward our current staff for their dedicated efforts and increase capacity to

serve those waiting for services.

1102 Task Force

One of the most significant bills passed by the Indiana General Assembly in 2018 was House Bill 1102. It established a commission to study and recommend action to improve services to people with developmental disabilities. This commission, chaired by Lt. Governor Suzanne Crouch, has met for the year, taken public comments, evaluated industry data and heard expert testimony. Meetings held around the state have permitted many people to participate in the process. The task force had its final meeting to present the report and the recommendations on October 19 in Columbia City. These recommendations cover a range from early intervention, housing, employment, technology and much more. This report is expected to guide services to people with intellectual and developmental disabilities for the next 10 years. More information is available on the state's website at <https://www.in.gov/fssa/ddrs/5455.htm>.

So, yes, we are very future focused. It's taken the dedication and determination of many constituents to get us where we are today, and it will not get any easier, but I am optimistic that we will have good days going forward. As Stone Belt moves toward its 60th anniversary celebration in 2019, we feel fortunate to have you as our friends and advocates. You've helped us come a long way and we'll go forward positively with your help.

With great appreciation,

Advocacy Lunch Series: Be ready to listen, learn, act

Learn more about Stone Belt advocacy efforts and why it's important to vote in every election at Stone Belt's three-part Advocacy Lunch Series — and bring a friend!

If you want to learn more about legislative issues that affect people with disabilities and how you can advocate for them, plan to

attend—and enjoy a free lunch, too!

Our lineup of speakers and dates include former Indiana Senator Vi Simpson on Thursday, October 25; The Arc executive director Kim Dodson on Thursday, January 24; and a state representative on Friday, March 29. All sessions are from 11:45 to 1 p.m., at Mile-

stones, 550 S. Adams St. in Bloomington. To allow planning for lunch, please RSVP to lmargison@stonebelt.org.

We all need to have our voices heard as legislators make decisions that directly affect people with developmental disabilities!

Why Vote?

Why is it important to vote? Why do we need to be active advocates for people with developmental disabilities? Historically, people with disabilities have been denied fundamental human and civil rights. It is a history marked by institutionalization, abuse and neglect.

Despite the great strides toward expanding the rights of people with intellectual and developmental disabilities, many obstacles still stand in the way of living fully inclusive lives.

Some — but not all — areas affected include:

Budget and Appropriations People with disabilities frequently rely on a number of federally funded programs in order to live in the community. These include **health care, education, employment, housing, long-term services and supports and transportation programs.**

Civil Rights People with intellectual and developmental disabilities have faced decades of hardship when it comes to exercising their civil rights. Issues range from being denied appropriate education, housing, transportation and more.

Family Support As our society continues to depend on the active engagement of family caregivers for the support of individuals with I/DD, it is essential to meet the needs of those caregivers to continue providing care in the community instead of more costly and unwanted institutions.

Medicaid Medicaid presents several issues for people with intellectual and developmental disabilities, especially because it has a strong institutional bias drawing funding away from home- and community-based services. Waiting lists, provider reimbursement rates, health care provider training and accessible medical are other Medicaid issues people with disabilities must face.

Social Security Millions of individuals with disabilities depend on Social Security programs to live, yet they face difficulty when the programs fail to meet the needs of the people to be served.

We also need to vote because people who provide direct care to people with developmental disabilities are underpaid and the workforce is plagued by frequent turnover. Voting and being an advocate for people with disabilities and the people who support them ensure that all people are able to live well and thrive.



MILESTONES

CLINICAL & HEALTH RESOURCES

a division of Stone Belt | milestonesclinic.org

New clinicians join Milestones

By **JAMES WILTZ**
Director of Milestones

By now, most people have heard about the challenges that agencies like Stone Belt have with staff turnover, especially at the direct support professional (DSP) level. According to the National Core Indicators (NCI) data, DSPs have an annual turnover rate that is nearly 50 percent. Stability is so rare that over 40 percent of DSPs across the US have worked in their jobs for less than one year. One reason for the high turnover is because these are mostly entry-level jobs, and there is so much competition from food service, retail and a hundred other businesses that need workers, especially at a time when the unemployment rate is low.

Milestones has fewer entry-level positions, and generally has experienced less turnover than the rest of the agency. However, 2018 has seen a sharp uptick in new employees in Stone Belt's clinical division. In the past year, we have hired new clinicians in every area of Milestones, including our Outpatient Clinic, Behavior Support Service, Skills Development Program, and Healthcare Coordination/Nursing. We also have new employees in our support staff.

Not all of our new employees represent staff turnover. Our services are continuing to grow, which requires more staff to meet the need. We also have hired some part-time clinicians for the first time. This allows us to have more flexibility in how we grow, and it also has given Milestones the opportunity to hire clinicians who were only available part-time. This has given us additional resources to provide robust clinical supports to our clients.

In the past year, Milestones has added the following people to our team. The Behavior Support team, headed by Mari Shawcroft, has added behavior clinicians (BCs) Sierra Hofmann, Tera Caster,



JIM WILTZ

Amanda Lamp, John Lamp, Keila Hawkins, Lisa Stewart and James Shepard. Skills Development, coordinated by Jennifer Hammond, has added skills clinicians (SCs) Alyson Aide, Eva Kiran,

Benji Loudermilk, Connie Rix, Genna West, Abe Carney and Kea Reed. Nursing services, managed by Khalil Stewart, has added nurses Melissa Sampson and Chris Schepper. And our clinic, with practice manager Deb Lane, has added two advanced practice nurses, (APNs) Jessica Bennett and Beth Murray, in addition to support staff Melissa Goodman and Teena Oliver. The clinic in Columbus also has a new therapist, Pam McCoy, who has been a BC for us for several years — now she splits her time between Behavior Support and Outpatient Therapy. In Bloomington, we have two new therapists working part-time. One is IU PhD student Qullian Murphy and the other is Carol Persley, our senior BC in Bloomington, who now works an additional day as a therapist.

Looking across programs in our clinical departments, it is pretty amazing how much transition there has been in the past year. It has been a busy time for the coordinators of those programs, but it is well worth the effort, and each has done a great job figuring out how to meet the ongoing clinical needs of our clients. It also reminds us of one of the important roles that Milestones plays in our community, which is training clinicians on how to apply their skills to the unique population we serve.

We certainly do not hope for this level of change each year, but it is good to know that we are up the challenge of finding people to fill the important roles throughout Milestones.

Clients, staff honored at celebration gala

Stone Belt hosted its most popular event of the year — the 2018 Stone Belt Annual Celebration — on September 17 at the Monroe Convention Center. About 600 people — a record! — attended the

gala. Bloomington Mayor John Hamilton, Monroe County Council member Shelli Yoder and United Way executive director Efrat Feferman were guest speakers. Congratulations to all the winners!



Client Self-Determination
Mary Swabb



Staff Self-Determination
Becky Mikels



Client Empowered Learning
Laura Marcum



Staff Empowered Learning
Kyle Beach



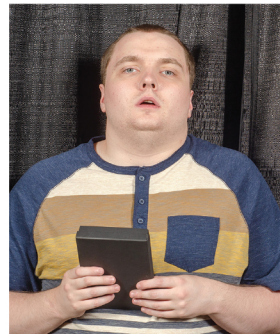
Client Outstanding Contributions
Nancy Vibart



Staff Outstanding Contributions
Rhonda Fair



Outstanding Volunteer
Rodney Margison



Client Positive Supports
Evan Turner



Staff Positive Supports
Benet Pearl



Client Self-Directed Home Life
Chase Himelrick



Client Employment
Edna Nichols



Staff Employment
Beth Ivey



Client Quality of Life
Bryan Hall



Staff Quality of Life
Alicia Wray



Elbert Johns Self-Advocate
Tommy Cunningham



Visionary Leadership
Susan Hoard



Steven Warren Hero
Miller House



Staff Self-Directed Home Life
Kim Mitchell Team

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Stone Belt appreciates our generous donors (October 1, 2017, to September 30, 2018) and their continued support. Every effort is made to ensure accuracy of this listing. If there is an omission, please accept our apology and contact Adam Hamel at (812) 332-2168 ext. 269 or ahamel@stonebelt.org.

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Corporate Giving

Becoming a corporate donor is a premiere way to show your support for people with disabilities. Be part of something meaningful and gain increased community awareness for your company. For information on how to make a

positive impact on individuals with disabilities and the many amazing benefits that come with being a corporate donor, contact Adam Hamel at ahamel@stonebelt.org.



UPCOMING EVENTS

ADVOCACY LUNCH SERIES

OCTOBER 25, 11:45 a.m.

Milestones Clinic, 550 S. Adams St.
With former Indiana Senator Vi Simpson

BEDFORD ART SHOW

NOVEMBER 17, 9 a.m.

Bedford Depot, Downtown

COMMUNITY ART SHOWS

ALL DECEMBER

Lennie's, 1795 E. 10th Street
Needmore Coffee Roasters, 104 N. Pete Ellis
Each location will be displaying select
work from Stone Belt artists. All pieces
available for sale.

DINING TO DONATE CAMPAIGN

ALL DECEMBER

Throughout Bloomington
Check our website for an up-to-date
listing of participating restaurants.

HOLIDAY ART FAIR

DECEMBER 7, 9 a.m.

Stone Belt Central Office, 2815 E. 10th St.
A sale of arts and crafts created by artists
supported by Stone Belt.

ADVOCACY LUNCH SERIES

JANUARY 24, 11:45 a.m.

Milestones Clinic, 550 S. Adams St.
With The Arc executive director Kim Dobson

It's the holiday season: Help us as you shop, eat

As you begin buying gifts and food for holiday festivities, there are several ways you can help Stone Belt and the people with developmental disabilities who we support. Please designate Stone Belt through these shopping partnerships:

Kroger Plus Community Rewards:

Register your Kroger Plus card online and when you use it, Kroger will donate a portion of your purchase to Stone Belt.

AmazonSmile at smile.amazon.com:

Designate Stone Belt Arc to receive a percentage of your purchases.

Before you go out to eat in December, check our website for an up-to-date list of eateries participating in **Dining to Donate**. Each will donate \$1 for specific dishes ordered in December.



If you would like to receive our publications, please
contact Linda Margison at lmargison@stonebelt.org.

www.stonebelt.org

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