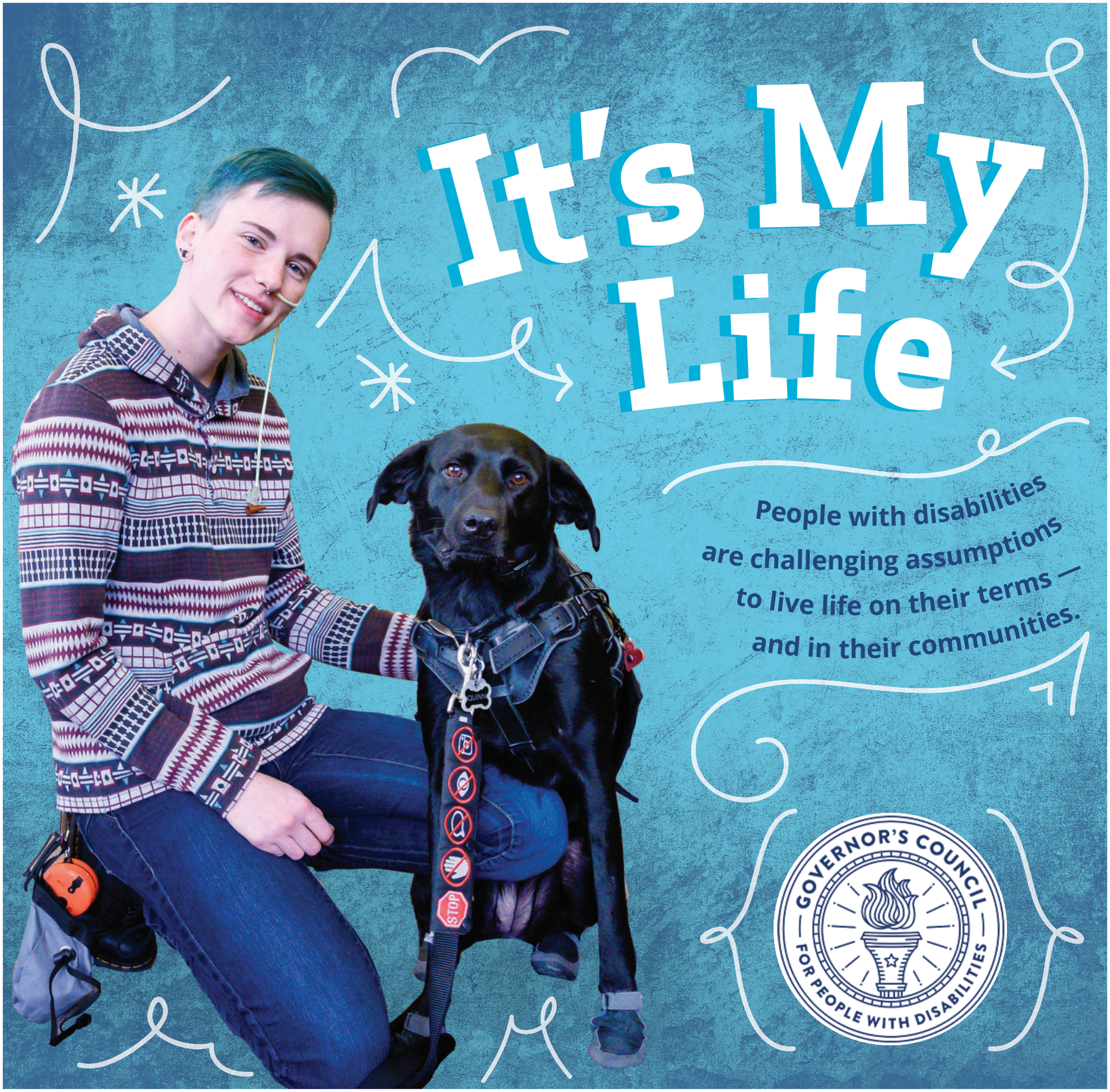
It's My Life

People with disabilities are challenging assumptions to live life on their terms — and in their communities.



GOVERNOR'S COUNCIL FOR PEOPLE WITH DISABILITIES

A Special Advertising Supplement

Diane Graves works as a mediator for the Indiana Civil Rights Commission, and has just completed her term on the board of the Indiana Governor's Council for People with Disabilities. She says society often underestimates people with disabilities due to lack of understanding.
PHOTO BY DOUG MCSCHOOLER

This Is My Life

Hoosiers with disabilities face a daily challenge: society's misconceptions

BY THEA MARIE ROOD

Like all inherent prejudice, it's easy to see a person with a disability and make certain assumptions: The person with her is a paid aide (not a spouse or friend), she must live somewhere, like a group home or nursing facility (not her own home), and she isn't employed (let alone is a professional with an advanced degree).

In fact, these negative perceptions are the biggest challenges people with disabilities face.

"A person who has sight cannot imagine how they would function — mix and match clothes, maintain a household, identify money, travel independently — without sight," says Diane Graves, who has just completed a six year term on the Governor's Planning Council Board, and is blind herself. "They just assume this couldn't be done and don't stop to think there are alternative techniques to be learned and employed that would enable the blind person to perform these same tasks independently."

This lack of understanding can also lead to people with disabilities being marginalized and their lives seen as peripheral to mainstream society. "Having a disability is rough — I won't lie about that," says Jody Powers, board chair for the Council, who was born with cerebral palsy and has mobility, vision, and speech impairments. "But my limitations are not as rough as living in a world where widespread ableism is tolerated — the idea that people with disabilities aren't as important as people without disabilities."

The Indiana Governor's Council for People with Disabilities aims to change public policy so that employers, real estate developers, educators and the general public can address the real issues involved. An important one: using a "consumer-driven" model, meaning the person with the disability is in control of the services they're offered and makes their own decisions. "These are our lives," says Powers. "We must have choices."

The council funds training for people with disabilities — and their family members — to better advocate for independence and inclusion. It also encourages affordable, accessible housing within the community through advocating for a variety of grant and rental assistance programs, as well as credits and design policies for developers. Finally, the council funds several employment initiatives in part to help educate prospective employers on the value people with disabilities bring to the workplace. "The major barrier, again, is the misguided notions held by society," says Graves. "We are often underestimated and people aren't sure how to relate to us."

> **"We are often underestimated and people aren't sure how to relate to us."**
>
> **DIANE GRAVES**
> Former Indiana Governor's Council for People with Disabilities board member

In the next few pages you will meet people who have hopes and dreams, people who are living in a comfortable home of their choosing, attending a highly ranked university, working a demanding career, getting married, having children. They just happen to do it while having a disability.

TERMS OF UNDERSTANDING

What does independence mean?

"Independence is less about doing things by yourself but rather being in control of what you do and how you accomplish it, and where you live," says Amy Sekhar, Ph.D., outreach coordinator for the Indiana Statewide Independent Living Council (INSILC), who uses a wheelchair and has a service dog. "I may not make the same choices as my peers, or even people with my same diagnosis, but my choice is ultimately mine."

What are productivity and inclusion?

Sekhar believes disability justice only occurs when people are fully integrated into their communities and can have an active role there. It also stems from a "consumer-driven" model of self-determination. "People with disabilities shouldn't be protected from their own choices — we should be able to enjoy and experience the full spectrum of the human experience," she says. "[And] productivity doesn't have to equate to employment — it can be any level of community participation, but we can only participate if we [have] equal access."

Back in Control

Jamie regained her independence under supported decision-making program

BY MATT CRAGGS

In 2010, Jamie Beck's stepfather passed away, her mother having passed years earlier. After losing her family, Beck — who has an intellectual and developmental disability — lost control of her own life when she was observed walking around the community and neighbors called adult protective services.

Beck was placed in a Richmond nursing home where Dan Stewart — then-president and CEO of Achieva Resources Corporation, Inc. — became her legal guardian.

For a year, Stewart tried to procure a Medicaid waiver that would get Beck out of the nursing home and into supported living. Finally, the waiver came through and Beck set her sights on getting a job in the community.

"I went all over Richmond," Beck says, "passing out my applications, trying to get a job interview. And when I did, I still didn't have a chance of getting a job because I had a disability."

After reaching out to the mayor and the city council, Beck got a job at a local pizzeria where she worked for four years while holding other jobs and volunteering, as well as being heavily involved in Special Olympics — where she met her fiancé, Kevin.

However, Beck's ultimate goal was a job with benefits and she found the opportunity in 2017 through the Erskine Green Training Institute (EGTI) in Muncie.

Run by The Arc of Indiana, EGTI offers programs where participants live and train at a local hotel while working in the community. Beck's program, Environmental Services, placed her at Indiana University Health Ball Memorial Hospital, where she quickly became a patient advocate.

In 2018, when the Supported Decision-Making Pilot Project came to Wayne County, Stewart knew that Beck was perfect for the program, which would dissolve his guardianship and allow Beck to legally make her own choices backed by a team offering financial, legal, housing and Medicaid advice and assistance.

After six months of preparation, the team went to the courthouse and made their case.

In June 2018 — when the court ruled in her favor — Beck became the first person in Indiana to regain full capacity, have her guardianship terminated in favor of supported decision-making.

"Afterwards," Beck says, "they asked me how I felt about it and I said, 'Yay.'"

"When she said, 'Yay,'" Stewart says, "the whole place started to cry."

Now, Beck lives with a housemate, gives talks at EGTI, and works at Ball Memorial Hospital.

"When I'm there," Beck says, "sometimes I even help out other students who are training for Environmental Services. Or I just talk to them and encourage them to do the best they can. I want to see them get a job in the community, like I did."

"She's helping folks," Stewart says. "I really believe in the next year we'll see others go through the same thing she did and it's because of her — her drive, her perseverance."

Ultimately, the transition to supported decision-making has given Beck her life back.

"It gives me a choice," Beck says. "I can and I'm able to help somebody else out, it's basically freedom that I've earned."

> **"It gives me a choice ... it's basically freedom that I've earned."**
>
> **JAMIE BECK**
> Patient advocate at
> Ball Memorial Hospital

After both of her parents passed away, Jamie Beck was placed in guardianship, meaning she was not legally able to make decisions about her own life. In June 2018, she became the first person in Indiana to have her guardianship terminated in favor of using supported decision-making under a program funded by the American Bar Association.
PHOTO BY DOUG MCSCHOOLER

EQUAL CHOICES, EQUAL COMMUNITY

Community inclusion comes down to choice. Under legal guardianship, a guardian can make life choices for an individual with disabilities. Conversely, supported decision-making creates a support network for the individual who makes the choice.

"Supported decision-making is probably one of the biggest movements that will help push everything towards integration," Dawn Adams says.

Adams, executive director at Indiana Disability Rights, believes people should have options and appropriate supports in order to make their own decisions to the greatest extent possible. She is encouraged by the current multi-state agency and organization addressing supported decision-making that would recognize the tool as a less restrictive option to guardianship.

"Knowing you have that support on your team," Adams says, "you can go out in the community, look for jobs, find roommates, and get to know your community, but still have that fallback of people that you can call and say, 'I need your help on this.'"

Ultimately, Adams believes the more choice an individual has, the more their life will be their own — both personally and within their community.

MAKING EDUCATION INCLUSIVE

Though support and services are crucial to students with a disability entering college, Pat Rogan, Ph.D., a professor at Indiana University – Purdue University, Indianapolis (IUPUI), believes inclusive attitudes and expectations are necessary to bring long-lasting change within the education system.

"Truly, we need inclusive education from day one," Rogan says. "We have to prepare a new generation of children who learn and play together."

Through her program at IUPUI, Rogan and Indianapolis Public School colleagues created college opportunities for youth with higher support needs who've finished high school with a certificate of completion but not a diploma.

"They are here on campus, auditing classes and having a college experience as we work with them to transition from school to adult life," Rogan says. "They're interacting with people their same age. They're engaged in volunteer and employment opportunities."

While the program opens college to students with intellectual and developmental disabilities, Rogan sees the benefits for all IUPUI students. Connecting on a human level — enjoying one another's company — creates a truly inclusive college experience for all.

The College Experience

Self-advocacy and campus supports have enabled Em to pursue a major and a minor

BY MATT CRAGGS

Going to college can be a big transition in anyone's life. For Em Mais, there was an added challenge.

"I got sick about a month before I started college," Mais says. "I stopped being able to eat any food. I dropped 40 to 50 pounds. My liver was totally on the fritz. My body stopped being a body — and that was my first semester of college."

Though Mais — who identifies as transgender or non-binary — has had their health fluctuate throughout life, the downturn preceding college presented a variety of new comorbid disorders that led to them becoming a part-time wheelchair user dependent on a nasal feeding tube for most nutritional needs.

Now a junior at Indiana University Bloomington majoring in psychology with a minor in gender studies, Mais juggles their condition and course load through self-advocacy and school services.

In addition to working ahead in classes to mitigate the impact of unexpected medical emergencies, Mais has also learned to navigate and insist upon the services and support offered by the university for students with disabilities.

Working with disability service coordinators on campus, Mais helps professors set reasonable expectations around the required support, such as using a laptop to take notes, recording lectures or being more flexible with attendance.

"A lot of classes have no or three absences allowed per semester," Mais says. "For students who are healthy and able-bodied, that's more than enough, but I've had semesters where going to class wouldn't have been safe or possible a lot of the time. Having that ability to stay at home and do what I need to do has made a huge difference."

Though Mais says most peers and professors have been great, there's still a tendency to judge Mais' abilities based on their appearance.

"It's important that you're setting reasonable goals and expectations for people," Mais says, "but don't assume that because you're in a wheelchair or have a feeding tube or a service dog that going to college or pursuing anything is not an option."

Even without the university's services and supports, Mais says they would still be pursuing a college degree — but their path would look much different.

"I wouldn't be a full-time student or attending classes on campus," Mais says. "It wouldn't be the college experience, and it's something that's important for me to have."

Self-advocacy and support services have ensured college remains an experience on Mais' terms.

"I will wear a breathing mask, I will run feeding tubes," Mais says. "But I am going to school."

> **"Don't assume that because you're in a wheelchair or have a feeding tube or a service dog that going to college ... is not an option."**
>
> **EM MAIS**
> Student at Indiana University Bloomington

Em Mais is pursuing a degree in psychology with a minor in gender studies at Indiana University Bloomington.
PHOTO BY DOUG MCSCHOOLER

Pride and No Prejudice

Support and high expectations help Jackson succeed in job at the library

BY MATT CRAGGS

Though Jan Bullington says her son, Jackson, has severe autism and anxiety and is considered low verbal and developmentally disabled, she never let the diagnosis define his capabilities.

"Jackson knows work is part of his life," Jan says. "His father and I set high expectations for him. We always believed he could and should be a tax-paying citizen."

In high school, the support and high expectations from his parents, the school, and especially from Laura Gandstad, youth assistant department head at the Hussey-Mayfield Memorial Public Library, led to Jackson volunteering at the library in his hometown of Zionsville.

In addition to learning the step-by-step tasks of employment, such as clocking in and out, the library staff and a behaviorist worked with Jackson and each other to create a work environment based in structure, consistency and routine.

Jackson was a good fit. Following high school, the library offered him a part-time job, which he's worked for the past six years — while also working at a local Walgreens.

Yes, Jackson has two jobs.

"Because I like to work hard," Jackson says. "Help people."

At the library, Jackson's responsibilities resemble those of any other employee.

"Put the books away," Jackson says. "Shelve media. Wrap holds."

> **"I like to work hard. Help people."**
>
> **JACKSON BULLINGTON**
> Staff member at Hussey-Mayfield Memorial Public Library

Jackson says his co-workers help him by finding misplaced books, making a list of things he needs to do, and encouraging him. And, with pride, Jackson says he helps his co-workers, as well.

"Fixing mistakes," Jackson says. "Help when people put the books in the wrong place."

Asked whether he enjoys the feeling of helping people, with a big smile on his face, Jackson replies, "Yes."

"He knows he has self-worth," Jan says. "He knows there's a place that needs him and wants him and there's a job to do and he needs to get it done."

Jackson also enjoys the more practical aspects of employment.

"You get money," Jackson says. "Buy lots of DVDs."

When not at work, Jackson loves watching movies, hanging out and participating in Special Olympics for the Boone County Stars.

While Jan says it's important for parents of children with disabilities to ask realistic questions surrounding employment, everyone deserves to try.

"Give them a shot, give them that chance," Jan says. "Don't assume someone can't work. If the first job doesn't work, go look for the second or the fifth until you find the job that works."

Asked if there was anything he wanted to add about his job, Jackson replies, "Yes I do. Thank you."

Jackson Bullington, seen here with library Youth Assistant Department Head Laura Gandstad, is proud to work at the Hussey-Mayfield Memorial Public Library in Zionsville, where he helps shelve books.

PHOTO BY DOUG MCSCHOOLER

INDIVIDUAL EMPLOYMENT FOR ALL INDIVIDUALS

When employing people with disabilities, Derek Nord, Ph.D., executive director of the Indiana Institute on Disability and Community at Indiana University, says the goal is individual employment, a synonym for the traditional employee-employer relationship.

"The main goal," Nord says, "is that everybody who wants a job has access to a job and the adequate services and support to make them as independent as possible."

Services and support may include résumé and interview preparation, job customization, and onboarding — and job coaching once in the workplace — for the employee and the employer.

"Supports can help the businesses understand how to train or work with the employee," Nord says. "It can help businesses to learn techniques such as task analysis that breaks down the job to smaller tasks that can be more easily taught to new employees."

Though it may require employers to move beyond their comfort zone, Nord believes the business community is one that wants to include people with disabilities who, in turn, want to work.

"If somebody with a significant disability wants a job," Nord says, "it's our job as professionals to figure it out."

BACK HOME

The Back Home in Indiana Alliance is a project of the Governor's Council and is designed to increase the availability of integrated, affordable and accessible housing.

"Its focus is solely on housing that is individualized and dispersed throughout the community," says Executive Director Deborah McCarty. "We want people to have access to typical housing." In fact, the project worked with the Indiana Housing & Community Development Authority to support the establishment of the Community Integration Reserve which gives a 10 percent annual credit to developers committed to reserving 20-25 percent of their units for people with intellectual or developmental disabilities.

McCarty also says the emphasis is on a person-driven model. "Choice is the underlying principle," she says. "And that includes who crosses your threshold."

For example, the project promotes visitability in the construction of single-family homes, which helps prevent people with mobility limitations from being isolated by architecture. Elements such as zero-step entrances, 31¾-inch interior door openings and a main level bathroom work for all members of a household and also allows friends and relatives with a disability to be guests in the home.

The Alliance also helps connect people to Housing Choice Vouchers. For those living in nursing facilities and other institutions, preferences for these rental subsidies are in place so people can return to life in the community with housing and supports.

Designing His Own Life

James can choose what he does and when he does it now that he has independent, accessible housing

BY THEA MARIE ROOD

James Gilliam lives happily in an accessible apartment on his own terms — something he never thought was possible before connecting with the Back Home in Indiana Alliance.
PHOTO BY DOUG MCSCHOOLER

Before a spinal cord injury paralyzed him from the waist down six years ago, James Gilliam not only lived in his own home, he was an architect and home designer. But the change in his health derailed his career and put him into institutional housing where everything was determined for him: what meals he ate, what time he woke up, when he could shower, when his sheets were changed and his laundry done.

It never occurred to him he could live independently again until 2017, when he connected with the Back Home in Indiana Alliance, a Council project, which advocates for accessible and affordable housing for people with disabilities.

"I didn't even know I could go through a process and get out of an institutional setting and get out on my own," he says.

Now he lives by himself in a bright and attractive two-bedroom apartment in Westfield, that has a roll-in shower, zero-step entrance and wider interior doors. It's one of several accessible units that are integrated into a community complex.

"I'm happy with my apartment," says Gilliam, but it's the freedom to set his own schedule and control his choices that matters most. "I have my own kitchen, and that gives you your options: some days you feel like a hot dog, some days you feel like a steak."

> **"I have … options instead of being forced into doing something on someone else's timeline."**
>
> **JAMES GILLIAM**
> Architect

He's turned one of the bedrooms into an equipment storage room, which also has two 8-foot tables for working on his architectural drawings. "It allows me to have some kind of thing to do besides watch TV," he says.

Gilliam's also arranged 12 hours of home health care each day, and his primary caregiver is a professional nurse who only sees to him, not 30 other patients, so her availability can suit his needs. "She has my routine down — she could come in most days and I wouldn't have to say a word," he says with a laugh. "She helps me with cleaning, cooking, laundry, personal hygiene, medical needs. I wake up about 8:30 every morning and she comes at 9 and we get started, versus someone showing up at your room at 7:30 in the morning or 3:30 in the afternoon. For me anyway, that is really annoying to have to live in that kind of situation."

In fact, Gilliam greatly appreciates the privacy having his own home affords him. "Some days I get up, some days I don't; some days I work on my drawings, some days I don't," he says. "I have those options instead of being forced into doing something on someone else's timeline."

A Melodic Love Story

After years of people not knowing the real her, Melody found someone who 'got her'

BY MATT CRAGGS

Melody Cooper's love story began as many such stories do, by learning to love oneself.

"[Relationships] give me the need to know who I am," Cooper says. "I think that's one of those things in life that people won't understand who you are."

Turning 50 in June, Cooper's life has been filled with people who couldn't see her past her cerebral palsy.

"I've been doubted and mistreated in my life," Cooper says. "Growing up with cerebral palsy, people didn't really know who I was — they didn't take the time. My teachers didn't know who I was. 'OK, this is Melody. She can't do this.' I heard the word 'no' so much."

Fed up, she came close to quitting school in the ninth grade, but her grandmother — who raised Cooper since the age of 2 — wouldn't let her.

"When I grew up, there was nothing for people with disabilities," Cooper says. "She knew I had to do something with my life. … She knew me better than I thought."

Cooper's grandmother helped her to understand what was important in life, but it wasn't the only relationship that helped Cooper become the person she is today.

At The Arc of Indiana — where she leads workshops designed to help people with disabilities understand they have a life outside of group homes — Cooper has become good friends with her colleagues. Together, they enjoy going out to eat, laughing and generally hanging out and having a good time.

At right, Melody Cooper met her husband Joe while they were both employees at the same worksite for people with disabilities. They've been married for 13 years.

PHOTO BY DOUG MCSCHOOLER

> **"It took me a while to find someone who understands me, but Joe understands me all the way."**
>
> **MELODY COOPER**
> Wife

"They took the time to understand me and ask questions of me," Cooper says. "They get it."

However, there's one person whose company she enjoys more than any other — her husband Joe.

"I met Joe and he just got me," Cooper says. "He just changed my world."

After meeting as co-workers at the same workshop, the two became friends, but life took them in different directions for 10 years before they reconnected and married.

Now, Melody and Joe have been happily married for 13 years.

"He knew what I wanted as a person and what I wanted as a human being," Cooper says. "It took me a while to find someone who understands me, but Joe understands me all the way."

In their marriage, Cooper says they support one another in reaching their goals, acting as a voice of reason, but never holding one another back.

"People told me, 'Melody, you can't do it,' and I'm here to tell you, I'm doing what I set my mind out to do," Cooper says. "Years ago, I opened up my mind to a whole new life, and now I can do what I want to do."

EQUAL RIGHTS, EQUALS HAPPY LIFE

For Kelsey Cowley, the lack of inclusion for people with disabilities in education and legislation is undermining many people's pursuit of happy and healthy social relationships.

"Marriage, family, kids, a job," Cowley says, "whatever makes everybody else happy will make us happy because we're human beings."

Cowley, vice president of Self-Advocates of Indiana, notes that people with disabilities are often excluded from sex education classes in school, denying them the power to understand their bodies and prevent or respond to abuse.

"The percentage is like 75 percent or more of people with disabilities will experience abuse, exploitation or rape in their lifetime," Cowley says.

While working to provide health education and resources to the community, Cowley also advocates for bias crime legislation and a reworking of how legal marriage and public benefits intersect. Too often, Cowley says, people with disabilities must choose to either get married or to keep public benefits, which may be their only source of income for necessary medications.

Cowley's ultimate goal is to run for elected office and to bring people with disabilities into the conversation.

Her campaign slogan: "Equal rights, equals happy life."

Be An Ally for People with Disabilities

Employers

People with disabilities want to work — they just need more opportunities.
Unemployment is high among people with disabilities, yet they have many skills to offer the workforce. “It’s just a matter of employers working with us to find the reasonable accommodations to help us do our best work,” says Jody Powers, who is the board chair of the Governor’s Council. “People can be our allies by thinking outside the box for solutions. Give us an opportunity.”

Housing Developers

Create affordable, accessible housing within the community.
While plenty of nursing homes and group homes are being built by developers, these types of housing segregate individuals. More regular housing options are needed, says Powers. It’s equally important people with disabilities can visit friends or family, something builders can achieve through zero-step entrances, first floor bathrooms and wider interior doors and closets. “We are often isolated because of accessibility,” says Powers, who uses a power chair. “It’s a civil rights’ issue, not just a ‘nice’ idea.”

Anyone

Find simple ways to help, like driving a friend or neighbor where they need to go.
One of the biggest challenges regarding independent life choices is transportation, says Diane Graves, a former board member on the Governor’s Council and a mediator for the Indiana Civil Rights Commission. “Someone who is unable to drive is limited in where they can live, work or play and have to depend on public transit or paratransit services, which have boundaries.”

Learn more and find out how you can take action at:

www.in.gov/gpcpd

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