

Home and Lifestyle

How do people with disabilities experience Madison?

Madison is becoming more accessible

By:

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Jane Earl is supposed to meet me at a west side coffee shop, but the brittle winter sky has broken into sleet, so it's too dangerous and I have to come to her. Earl has muscular dystrophy and she's in a power scooter, which is usually not the first (or even the second or third) thing she'll tell you about herself, because she never knows how it will color your perception of her, what assumptions you'll make, what conclusions you'll draw. Today she doesn't have a choice about disclosure—I already know this pivotal thing about her; it's why I'm here. And it works out kind of perfectly anyway, because I can see, firsthand, just how inaccessible almost everything can be.

I plug the meter and jay-dart across the street to her downtown high-rise, pull the heavy front door against the usual vacuum and slide inside where it's warm and dry. I've already texted her that I'm here, but now I press the buzzer and wait, probably three or four minutes, for her to make her way downstairs from the tenth floor. She motors up in an elegant burst of color—bright apple-green top, coral scarf wrapped around her slim neck—and flashes me a dazzling smile. After decades of high-profile positions all over the country in both the corporate and nonprofit worlds, she knows by now how to make an entrance.

Earl shares a cozy, modest two-bedroom condo with her husband, former Wisconsin governor Tony Earl. She tells me they spent “megabucks” fixing it up with accommodations for her disability, but they have less control over the accessibility of the rest of the sixteen-floor, 174-unit building. Like her seemingly rock star parking space, for example, in the adjacent indoor garage. After the lengthy elevator ride upstairs but before heading down the long highway to Earl's unit, we stop so

she can show me her parking dilemma. Each floor of the building has a set of doors that lead directly out to the parking structure, and Earl's got the "handicapped" stall right next to the doors on her floor. But it might as well be miles away.

"This is classic," she says, in the ramp, next to her car—now retrofitted with a lift for her scooter so she can travel without assistance—as we contemplate getting back into the building. The door between the garage and the condo is not automated. It's a door like any—standard steel, very heavy, with a slim silver handle you pull to open. I see now what I wouldn't have seen before, even though I've just walked right through it: it's pretty much impossible for someone in a chair to open the door.

Earl's got a system, though, one she's been forced to develop after a lot of trial and error: Using the controller on the right side of her chair, she drives up to where, if she positions the chair at precisely the right angle and leans her body forward, she can just reach the door handle with about an inch of clearance between the base of her chair and the foot of the door. Then, with several forwards and reverses, she uses the power of the chair to slowly pull the door open.



As I watch her navigate this aggravating ritual—and I'm not proud to admit this—I grow increasingly uncomfortable. It's taking everything in me to resist the urge to reach out, just grab the door, and yank it open for her. She finally manages to get the thing propped open just enough to wedge herself inside it, fashioning a doorstop out of her right leg, then gives one last quick pull, lets go and quickly motors forward. And I unclench, until I see our reward: a second non-accessible door. And so the excruciating process is repeated, this time in an even tighter space. (In the early days, while attempting to make it through this second door, Earl powered straight into the wall on the other side, resulting in smashed drywall, an expensive, out-of-pocket repair, and more than a little embarrassment and frustration.)

Technically, because of the elevator and the power doors at the front entrance (automated only for those who have a special key fob, for which Earl had to pay \$50), this building is legally “accessible.” Although Jane is not the only tenant in a wheelchair or scooter, the condo association has understandably voted down the \$44,000 it would cost to automate the parking garage doors on all sixteen floors (Jane says she’d be satisfied with just one door, on any floor, which she conjectures would cost significantly less in return for immeasurably higher property value). Their solution is for Jane to take the elevator down to the front entrance, exit the front door, travel down the sidewalk and around to the parking garage entrance, drive her scooter all the way up the ramp to her floor, and retrieve her car from her parking spot next to the door. On most days, that’s an inconvenience very few of us would tolerate. On icy days like today, it’s a dangerous risk she can’t afford to take.

“I am a strong-willed person. I’m a confident person,” says sixty-two-year-old Earl, who was diagnosed with this adult-onset, progressive disease in her mid-twenties, one week before her wedding to her first husband, when she went in for her marriage physical. Even as recently as four years ago, when she moved into Tony’s condo, she did not yet need a scooter. “And there still are days—and not very often, because I don’t make a habit of feeling sorry for myself—but there are days where the situation is so frustrating that it nearly brings me to tears.”

Earl has lived a lot of places, and admits Madison is actually pretty good in comparison. Our people are forward-thinking, kind, educated, well-meaning. We’re sensitive to the virtues of diversity and inclusion. Our streets are relatively smooth, the crosswalks squawk clicks and warnings, the sidewalks have curb cuts—although we forget this when it snows and we clear everything but them, making for treacherous, often impassable routes for people in wheelchairs as the rest of us tromp on, oblivious. We have a thick resource network of county and city agencies and private and grassroots advocacy groups delivering services and support to people with disabilities of all kinds. We have a public paratransit system, and flexible, progressive partnerships between school and local government for integrative classrooms and inclusive employment. We have entrepreneurs and innovators creating assistive technology. We have world-class healthcare, research and development facilities. And still, all over the city, every day, we have neighbors who can’t even get through the door.

Both literally and figuratively, getting through that door is at the crux of most any conversation about disability rights. Universal access is a difficult thing to define, and the last thing anybody living with a disability wants is to be lumped in with everybody else. Earl happens to be one of the roughly four million Americans who will depend on a wheelchair or scooter for the rest of their days, but an estimated thirteen percent of us will temporarily use a wheelchair at some point in our lives, whether after injury or surgery, or the inevitable complications of just plain aging. And—this is important—while people with conditions like muscular dystrophy, multiple sclerosis, cerebral palsy, ALS and spinal cord injuries may require wheelchairs and other accommodations,

they certainly demand very different resources and support than those who have cognitive and developmental disabilities. And those two groups differ even further from those with visual or hearing impairments, or serious and persistent mental illness, or any number of other conditions on the long list of what constitutes “disability.” We’re talking about a vast, broad, wildly diverse group of people here.

But for all the differences, there is a core common thread, according to the city of Madison’s Jason Glozier: the “othering” effect. It’s that thing that makes you different, sometimes isolated, maybe even invisible. And as painful and frustrating as that may be for people with disabilities, he says, it’s shortsighted to think they’re the only ones who suffer. What do the rest of us lose out on when we block or ignore the potential contributions of an entire segment of the population? When we, literally, don’t let them in the door?

“By losing that experience of people with disabilities, we lose the breadth of the experience of life,” says Glozier, from his seat where we’ve met at a popular downtown coffee shop. The place is packed and, after we’d zigzagged through the crowd and tightly clustered tables to snag a prime seat by the window, Glozier matter-of-factly points out how impossible that would have been, had either of us been in a chair. “We don’t think about the fact that stairs are a deterrent to people. We don’t think about the fact that education isn’t equal. We don’t think about the fact that all these systems are designed to support people like you and me, and we keep designing systems just like that. But we all benefit from improvements that come from accommodating people with disability.”



Jason Glozier

Glozier’s official title is disability rights and services program coordinator, housed in the city’s Department of Civil Rights, which came about in 2006, after a somewhat controversial merger between Affirmative Action and Equal Opportunities. Up until now, the city has budgeted for these three services as separate entities, but the 2015 proposal indicates consolidation into a single “Civil Rights” entity to reflect the department’s “collaborative approach and broad mission to ensure the City’s employment and community activities are equitably undertaken.” Maybe that’s courting even more controversy, financially speaking. Or maybe it’s evidence of just how much Madison is expanding its views on what it means to be an “accessible” city for everyone.

On the surface, Glozier’s job is to review all the city facilities, buildings and parks that go up in town, to make sure they’re adhering to accessibility laws, not just in letter, but in spirit. It’s an important distinction, because he believes his real job is to ask us all to look at things a bit differently. He’s got an insider’s perspective as a child of disability activist parents, ones who always fought—peacefully, but very visibly—for equity and integration for Glozier’s brother, who has cerebral palsy. He knows from personal experience that just because a building like Earl’s

appears to be accessible, it isn't, really, and that there are scenarios just like it unfolding all over the city. He knows there are very popular, very highly regarded restaurants in Madison that his friends in wheelchairs can't get inside, because buildings constructed before the Americans with Disabilities Act are not required to be accessible if doing so isn't "readily achievable" or costs an "undue burden," according to the ADA. Or that a playground—critical to childhood development for all kids—might actually inadvertently serve as yet another barrier. (Take that rubber chunk ground covering, for example. Accessible by legal standards and installed in parks across the country with the best of intentions, a little common sense tells us that it's anything but easy to walk or wheel across—have you tried it lately?)

"It's about building awareness capacity, because people aren't aware of what they're not aware of," says Glozier, and that's the thing: his peers already have these values of inclusion and diversity, it's just that "people simply don't understand disability until they're affected by it." And even then, we tend to take an individualistic approach—but Glozier wants us to think as a community. He wants us to do more than the bare minimum (which is all that so many of our laws require) because our buildings and systems still exclude people unintentionally.

"I could use the hammer of the law and say this is what you have to do," he says, "but I've found that building the bridge to what people value is the best way to start making some of this social change."

And it's working. Glozier says he's been blown away by the many ways his peers have willingly gone above and beyond the letter of the law, from little improvements all over the city, to a brand-new, seven-thousand-square-foot, universally accessible playground—the first of its kind for city parks—in the works for 2015 or 2016. Of course, funding is always an issue, but when basic things become commonplace, the cost is far less and the gains far greater. Glozier points to the city's most recent crown jewel, the Central Library, as an exquisite example of designing with accessibility in mind from the very start, so that you don't have to invest in expensive retrofits on existing buildings. Imagine what could happen, he says, if we built things the right way—buildings, systems, programs, housing, employment, education, social systems, everything—from the ground up? To do this, we all have to believe that we're all in this together, that there's a very real benefit for all of us. We're not there yet, but Glozier is hopeful, particularly if we can start to look at people with disabilities as fully fledged citizens in a community empowered by their neighbors. His personal background makes it natural for him to see people with disabilities as entitled to this power, but that's not the way the rest of us are used to looking at things.

"It's not the paradigm of disabilities that we're framed with," says Glozier. "It's most often the most disempowering thing that exists. And it's usually framed in these aspects of pity and paternalism and fear."



Glozier also works on the city's Racial Equity and Social Justice Initiative, which brings us back to that collaboration idea within Civil Rights. Just as Madison has begun to come to grips with the way its been blatantly failing its people of color—not through outright racism, necessarily, but by privileged participation in systems that are inherently biased—so, too, can we start to see how we have rendered people with disabilities, at times, invisible. That same paradigm shift is necessary for people with disabilities, he says; it just hasn't fully happened yet. In some ways we're miles ahead of where we were. In others, we're breathtakingly behind, despite all these laws. Those with disabilities are the only people for whom it's still legal to deny minimum wage, for example, which is nearly as unfathomable as not being able to get in a building. Nobody is inferring that race is a disability, that's utterly ridiculous—but the more subtle, multilayered, unintentional ways in which majority culture discriminates can be chillingly similar.

"We ended the process of people of color going through the back door fifty years ago," says Glozier. "Is that still a common practice that we have in the disability world? Absolutely."

Part of the reason that some of this inclusion and integration stuff might still feel a little awkward is because it's a relatively new concept. Up until thirty or forty years ago, when the deinstitutionalization movement started to unfold, we "took care of" people with disabilities—particularly developmental disabilities—in segregated settings like group facilities and sheltered workshops. This idea of serving people in their homes, or in our schools, in our parks or in our workplaces, was sort of radical in your parents' generation, possibly even in yours. The Americans with Disabilities Act, which not only prohibits discrimination based on disability but requires people and places to make "reasonable" accessibility accommodations, didn't even exist until 1990. And while a spate of other state and federal laws have been enacted to mandate and protect certain rights, of course you can't legislate shifts in perceptions or attitudes. You can't expect people to start seeing barriers for people with disabilities after lifetimes of not seeing people with disabilities at all.

Doug Hunt works for Dane County Human Services as the vocational services manager in the developmental disabilities unit, but he tells me his main job is to work on employment issues for adults with developmental disabilities. I ask him for a brief, local history and he tells me about Lou Brown, a UW professor in the Department of Rehabilitation Psychology and Special Education from 1969 to 2003, whom he credits as a pioneer in developing models that could prepare students with disabilities to integrate fully into society. He says parent advocates then led the charge to not only get support in schools for their kids, but to enlist the school district and Dane County in continuing that help into employment once they graduated—which brings us to today. He says there are more than eight hundred people with developmental disabilities working at around six hundred Dane County businesses as part of what's called Supported Employment. Between eighty-five and ninety-five percent of the forty to fifty young adults with developmental disabilities who graduate from Dane County high schools each year go on to community jobs.

Obviously this is good for people with developmental disabilities; it gives them access and opportunity, a chance at that same sense of identity and pride and satisfaction that we all get from a good day's work. But this isn't nearly as simplistic as benevolence, and it goes even further than the aforementioned arguments for why we all need diversity; Hunt says there are good, solid business reasons for employing people with disabilities.

“We find the people who are working in the community generally are very reliable, have really good attendance, are eager to work, and just by their presence in the workplace often add enthusiasm and a positive element,” says Hunt. “I think that’s probably one of the eye-opening things for employers if they haven’t had much experience in the disability field, is how many unique strengths an individual with a disability can bring to the workplace.”



The turnover rate for employees with disabilities is eight percent, as compared to forty-five percent for other workers. Furthermore, eighty-seven percent of customers say they would prefer to patronize businesses employing people with disabilities—we look favorably upon companies for providing these opportunities and we’re more likely to spend our money there. It transitions people with developmental disabilities into tax contributors, and let’s not forget that their families and friends need places to spend their money, too.

“Those eight hundred people generate \$3.6 million a year in wages, and virtually all of that money gets plowed back into the local Dane County economy,” says Hunt of the \$12 million Supported Employment program, funded with county, state and federal dollars. “Because those are folks who live and work right here, either on their own with support or with their families.”

Something that’s especially cool about the way the county has chosen to find individualized employment for people with developmental disabilities—something maybe all of us could learn a little bit from—is how they match people to jobs. Most with these disabilities aren’t going to be able to meet all of the requirements of a standard job position posting, so it becomes important to figure out their individual skills and match those to a specific need.

That’s the very same thing that former restaurateur Nancy Christy accidentally made a living (and a reputation) doing when she and Andrea Craig opened Wilson Street Grill in 1987, in a spot known as “the black hole” because three previous restaurants in that space had failed. The partners never set out to make a statement when they determined that one third of their staff would be people with disabilities. They certainly never expected the national media attention, or the awards and accolades. For Christy, it just felt right. Bringing together people who cared about other people and loved what they did—whether that was creating a gourmet dish from scratch or simply sweeping the floor—was the way she wanted to spend her time.

“What started out as this kind of idiosyncratic desire to pull my interest in people and my interest in food together ended up as a picture that benefited everybody,” says Christy. “Benefited our business, our employees, our turnover, our everything. And that was such a surprise.”

Much as Hunt described, Christy, rather than hiring to fit a job description, hired people, pinpointed their skills and passions and gave them those responsibilities. Not only would that particular task be performed really, really well, but sometimes people who were initially perceived

as having very limited capacity blossomed under the unique conditions. Take Roger Touchette, who came to the Grill from the Yahara House, a Journey Mental Health–facilitated, national clubhouse model that supports people with severe and persistent mental illness to secure employment. In the beginning, Touchette’s only job was to weigh the dough and press it into a bread pan. At first he required daily assistance, but six months later, he was doing it on his own. And, eventually, he was doing all kinds of things.

Touchette crushed, cut and roasted all the tomatoes. He picked and prepared all of the herbs. He was coming in early and staying late. He was working on holidays when the restaurant was closed (“The manager came in so that Roger could work because he just couldn’t stand not coming in,” says Christy.) He stayed for years, as did so many of his coworkers, with or without disabilities, in an industry traditionally fraught with high turnover. Even more surprising, many employees would open up about their own profound struggles, because they felt safe and supported in an environment where “we all have abilities and disabilities, bottom line.” Christy spent far less time hiring, interviewing, and training new people because the existing people stayed—and they brought their friends and their families, and they celebrated their birthdays and they toasted their anniversaries, and the Grill had a really solid, really successful, fifteen-year run.

It wasn’t a utopia, by any means. Running a business this way took time, money and patience, but it had rewards that border on rare for a lot of us in our careers. It provided Christy a quality of life that comes only when you’re truly living in synchronicity with your values, and so she’s clear that she’s the one who really benefited. And although she was “not a trained disability person” and the Grill closed for good more than ten years ago now, she’s still held in high regard by the disability community for creating and cultivating an integrated workforce model that worked. What she did was considered innovative back then, but Christy says today’s business climate is perfectly positioned to do the same thing. So many companies are already prioritizing sustainability and diversity, they just aren’t necessarily thinking about integrating people with disabilities as a key part of that.

“People can understand sustainability, that it’s good for the whole—but they haven’t been able to quite see hiring as part of that sustainable concept,” says Christy. “Biodiversity, and I think diversity in general, it enriches everything. It comes with its own set of issues, but the payoffs, I think, are worth it.”



Building bridges: At LOV-Dane, Amanda Bell (right) helps connect members like Daniel Ellis (left) to passion projects.

Amanda Bell is living in sync with her values, too. Just about nine years ago now, after ten years as a special ed teacher at West High and Sherman Middle schools, Bell took a job at a Dane County-funded, UW Waisman Center-affiliated project called LOV-Dane, or Living Our Visions. Her job (and LOV-Dane itself) started out as a proposed solution to the “waiting list” problem—essentially, a growing number of families waiting for county funding and resources once their kids with disabilities left high school. That number of kids transitioning into the community has risen at a rate of between twenty and fifty a year, while annual budget cuts have restricted (or shrunk) the pool of money that supports them. It’s a complex issue, no doubt, but Bell was charged with addressing only one piece of it: if the money isn’t there but the need for—and, more importantly, the county-recognized value of—community inclusion still is, what do we do with families on the waiting list in the meantime?

“There’s a growing number of folks within the developmental disability system who might have a little bit of support to work but who don’t have enough support to move out or to necessarily get the full life that they want,” says Bell. “You can have a good inclusive life and be part of school clubs and part of regular ed classes and have those relationships, and then you leave school. And while Dane does a great job supporting people to be employed, that still is not the same kind of life that school offers. That is a big transition for people.”

So Bell set out to help families work outside the system to create their own personalized solutions. She dove in at the grassroots level, inviting herself over to people’s homes for coffee, listening hard and looking for common threads. Right away, it was clear that these families were often isolated from each other but wanted the same things. They wanted connection. They wanted to contribute to and participate in their communities. They wanted the same thing we all want: quality of life. But they needed help.

“And so we started with eight people in a living room saying, what could we do together that we can’t do by ourselves,” says Bell. “And now we’re about 130 families.”

Those families are no longer limited to those living with developmental disabilities—anyone with a disability who needs that connection and support is welcome (“You’re a member if you say you’re a member”) and all LOV-Dane programs are family designed, family run. Bell and her team’s job is to find the issue and pull people together, to not only draw on the community connections they’ve developed over the years, but to support families in exploring their own networks—a neighbor who’s a property manager, say, or an uncle who’s an electrician, or a former employer who’s an artist. As she puts it, her job isn’t to deliver services, it’s to “help get people in a room and move what they want to do forward.”

LOV-Dane has a lot of irons in the fire—support groups, outings, voting drives, employment opportunities, housing solutions—but the longest ongoing project is probably Bridge Builder. Several member families pooled their money to hire a person to act on their behalf on the ground, to facilitate relationships between them and other people out there in the community. Families created the concept, wrote the job descriptions, developed the budget and eventually hired two full-time Bridge Builders. The project goal is to help people with disabilities find their passions and contribute to the community in a way that benefits everyone.

LOV-Dane member Daniel Ellis, for example, wanted to try woodworking—and now a guy named Tom Liebl hangs out with him once a month, having coffee and building Little Free Libraries and bat houses to put up around town. Steven Clerico wanted to join a faith community but has the

sort of disability where he needs physical support all the time, and that's expensive; the Bridge Builder joined Clerico at his new church until its members built a natural relationship with him and organically took over helping him get there every Sunday. Or take Jon Glenberg, a guy who dreamed of joining a travel circle in Madison, basically a group of people who could get together to talk about the trips they've taken. When Glenberg couldn't find one, he created his own.

"What's lovely is Jon got to be the instigator and actually develop something that is an asset and a gift to Madison long term, because it was his passion," says Bell. "At LOV-Dane, we're really committed that it's not 'token inclusion.' It's reciprocal inclusion. We really believe that there's something more that can happen if both the person and their family and the community groups get a little bit of nurture to see it."

When it became increasingly clear that many people with developmental disabilities had no idea what their passions were, because they'd never really been asked or had the opportunity to explore such a question, LOV-Dane came up with this idea called Samplers. They connected with UW Wheelhouse (formerly Mini Courses) and Lussier Community Education Center to bring in groups of members and let them try different classes. True to Bell's philosophy, it wasn't only LOV-Dane members who benefited from the collaboration.

"The Wheelhouse staff figured out that actually having connections to these young people with disabilities was fabulous and they wanted more of it," says Bell. "Now we get to work with them to figure out what the barriers are to having these people be able to join the 'regular' Wheelhouse classes. How do we work through it so that in fact people can get connected."

Of course LOV-Dane families, like all families with disabilities, still very much need the resources and support of taxpayer-funded systems. Of course, Bell and others are worried about the increasing strain on a local government that gets it, but can't necessarily sustain the current model forever. In working from the ground up, she's run right up against systemic barriers, ones that require systemic solutions—like transportation, for instance—and she knows she couldn't do so much of what she does without the system. But she'll continue to mobilize at the grassroots level because that, she believes, is a fundamental part of the long-term solution for all of us.

"LOV-Dane's theory is, build really good stuff, because if you build good stuff," says Bell, "any system change is less likely to take it apart."

You might have noticed that we've sort of transitioned—ideally, expanded—this conversation to people with developmental disabilities. And perhaps it bears repeating now that we get it: people with developmental disabilities have very different needs and challenges than those who primarily struggle getting their wheelchairs in and out of buildings or events. That's because this is not some brazen attempt to cover all things "accessible" for all of Madison; it's to look for the core similarities, like Glozier's "othering" effect. Glozier, Bell, Hunt, Christy, they're all saying essentially the same thing: awareness changes everything. And when we become more aware, this stuff just makes good sense. There are very basic things that too many of us are still taking for granted that are still denied to so many people with disabilities, and there are equally basic ways we're all denied the experience of living among people with disabilities of all kinds. Barriers don't just deny basic rights to some of us; they eliminate the critical normalizing effect that mainstreaming has on the rest of us.

“I think the corrective for me is to remind myself to look for capacity, rather than to look for dysfunction or disability or difference,” says Howard Mandeville, who retired last year as executive director of Movin’ Out Madison. “How can we support people where there are gaps in capacity, and really see people in terms of what they can contribute, what they can do, the value and merit that they bring to their existence.”

And ours. Movin’ Out is a nonprofit that provides “housing solutions” to people with disabilities, not only to provide the tools to access four walls and a roof, but to help create a sense of home. And a critical part of that is building a life in a neighborhood, in a community, with all of us, for all of us. Home represents safety, warmth, nourishment, connection, identity, independence, stability. Everybody knows there’s no place like home.

“So when you think about all the stuff that we load into what home is, no wonder it’s an important thing for any of us,” says Mandeville. “And then it’s all the more bewildering that for vulnerable people—people vulnerable because of their disabilities—we would erode or erase the opportunity for people to actually have that kind of calm.”

So, over the past fifteen or so years, Movin’ Out has collected a portfolio of properties—single-family homes, duplexes, condos, essentially existing housing in existing neighborhoods—that they’ve purchased, fixed up and rehabbed for accessibility.

Mandeville knows that deinstitutionalization is not the same thing as fully integrating people with disabilities into our communities. It’s one thing to retrofit old homes with accommodations or create new buildings from the ground up with universal accessibility in mind, quite another to foster integrated neighborhoods where people of all abilities have regular, day-to-day interactions with one another.

“What we’ve seen over a couple hundred years of separating people with disabilities from their communities and their families, concentrating them in one place, it isn’t what people want and we’ve learned it isn’t good for people,” says Mandeville. “It emphasizes the vulnerability associated with disability, because if they’re seen as so different than the rest of us that they need to be served in these special settings, isolated from the normal flow of the community, that’s stigmatizing. And it creates consequences for people that are worse than the attributes of their disability.”



It’s in this spirit that Movin’ Out is embarking on what could be characterized as its most ambitious project to date: Dempsey Place, a partnership with Stone House Development in the Royster Crossing project on Cottage Grove Road, one bolstered by city and state affordable housing tax credits and private financing. While Royster Crossing will provide a mix of retail and hundreds of housing units, Dempsey Place will include seventy one-, two- and three-bedroom rentals, about a quarter of which will have enhanced accessibility features (roll-in showers, wider doorways,

barrier-free floor plans) and an equally important feature of accessibility: affordable rent for people with permanent disabilities (along with military veterans and those needing workforce housing). There's the added bonus of the surrounding redeveloped neighborhood providing employment opportunities and services for people with disabilities literally in their own backyard, and there's something more, too: visible inclusion, integration, a sort of normalizing and mainstreaming by design. And that's a big deal.

"What we're doing is creating a context for people with disabilities not to be concentrated with just other people with disabilities, but more integrated into a natural community. There's this intention to create a more diverse, more welcome community for all kinds of people," says Mandeville. "So it's another way of creating opportunities for people to have an identity, other than just a disability. They have an identity as a neighbor, and as a tenant or a homeowner. And [they] are a part of what's going on where they live."

I'm walking into another coffee shop to meet another person in a wheelchair and, like Jane Earl, Brett Masbruch would rather disclose that information to you on his own terms. But it just doesn't work that way when you've got cerebral palsy, or any other significant disability. We see the condition first, the person second. Besides, so many times when he's disclosed his disability, doors have shut—however gently—in his face.

This time it's an unseasonably warm day and so the weather isn't an issue, but transportation is, he tells me, from the table he's snagged right by the door. He's been here fifteen minutes already and he'll probably be here fifteen minutes after I leave, because he has to schedule such a wide window with Madison Metro's paratransit system. He also, as an east sider, has to be careful about where we meet; parts of his neighborhood fall into Monona, and that's not technically Madison, and Metro Plus services only within the city limits. On the one hand, he feels grateful to have the resource. On the other, it can be wildly unpredictable. And it always serves as yet another reminder of something the rest of us take for granted that is completely out of his control.

"My passion for accessibility really started after I lost my first job," says the forty-two-year-old Madison native, who is a clinical substance abuse counselor with a master's degree in mental health counseling. "I'm realizing that all the places that I would want to work at aren't accessible."

Masbruch has gotten to know ADA law by default and he's more familiar than he'd like to be with many of the apparent "loopholes"—buildings with only two floors aren't required to have an elevator; you don't have to install accessibility modifications if you can prove financial hardship or if your building is a certain age—and he also measures accessibility in two parts: can he get in the building, and can he do his job once he's inside? It's usually this second part that doesn't work out, because these are the kinds of issues most of us still aren't seeing. Can he reach the overhead cabinet? Can he get to the copy machine? Can his chair make the tight corner into his office? Most of all, to take it a step further, if any of his or his colleagues' patients have disabilities, can they access these mental health services?

Masbruch and I have a long conversation on this day. We talk about his passions and his challenges. We talk about the balance he's always trying to strike between coming across like the "accessibility police" and leaving each job or space or friendship a little bit more accessible than he found it. We talk more about transportation, and snow removal, how he doesn't even try to be a part of iconic Madison experiences like Brat Fest or the farmers' market. About the assumptions

people make, about the way he's so often patronized or condescended to, because his body is bound to a chair but his brain is as sharp and average as yours. We talk about how he's a member of the Recovery Coalition of Dane County because he wants to work from the inside to make his entire field more accessible to addicts and alcoholics with disabilities, because it's a large market with an unmet need. About how he'd love to serve as a consultant in general for people who are designing buildings and systems, to help them see what they're not yet seeing, from his chair.

I know I'll never get all of his concerns down in these pages. I know I'll never even begin to scrape the surface of this complex topic at all, or effectively describe the budget concerns from all sides, or tell about all the different boards and agencies, businesses and groups doing really important work in this community. But I ask him anyway, because it's the same thing I ask everybody, on every story like this I write: you've got five minutes in an elevator with all of Madison. What do you most want people to know?

He takes a while to think it over, and I imagine him sifting through the long laundry list of critical legal and practical issues facing people with disabilities. I imagine him weighing each one carefully, prioritizing what he'd most like you to hear, if given just one chance. And I'm so surprised when he finally says what he says.

"Just," he says, before pausing again for a few more seconds, "just know we're out there."

Reinventing the wheel

The wide-open field of assistive technology is ripe for revolution



On a Roll: Rowheels is poised to transform the wheelchair industry by offering wheels that a user pulls rather than pushes.

Serial entrepreneur Rimas Buinevicius spent only ten weeks of his life in a wheelchair, but it changed everything. The former Sonic Foundry CEO and co-founder of the Madcelerator early-stage business incubator slipped while sailing in 2011, suffering a spiral fracture on his leg. After only three days in a standard, medical-grade wheelchair, he was fed up with shoulder pain and the difficulty of pushing. And as a guy who'd built a career based on thinking outside the box, he just knew there had to be a better way.

Four years, a partnership with quadriplegic NASA inventor and scientist Salim Nasser, a 2012 Governor's Business Plan grand prize and a new Madison business later, Rowheels is poised to potentially break the \$2 billion wheelchair market wide open with its brilliant, seemingly basic innovation: Why push when you can pull?



“When you look at a rowboat, it’s not called a push boat; it’s called a rowboat for a reason. And that’s because it’s just easier on your body,” says Buinevicius of the wheels that easily attach to most any standard manual wheelchair on the market, allowing its users to pull instead of push. Rowing actively engages eight of nine upper-body muscles; pushing, on the other hand, engages only two, often leading to chronic pain and repetitive stress injuries, and the sort of hunched-over posture common to long-term wheelchair users. Rowheels is in the beginning phases of production here in Madison (using many Wisconsin manufacturers, including Madison’s Saris Cycling Group for the rim, tire, tubes and spokes), while the marketing team is out introducing it to the health care industry around the country at places like trade shows and hospital and medical centers’ in-service trainings.

“I’ve had in-service sessions where literally the nurses were crying,” says Buinevicius. “It’s really rewarding, because you get into these in-services where the people really know what we’re doing because they’ve been treating this forever, and that’s where I think people really get blown away by it. And it hasn’t even hit the market en masse yet.”

Buinevicius never set out to make anybody cry, or even make anybody’s life easier—he just saw a gaping need and an entrepreneurial opportunity. That’s kind of how it went for Jay Martin, too, a UW–Madison engineering professor who, in 1999, experienced the worst: his sixteen-year-old son, Liam, suffered a cervical spinal injury in a diving accident that left him paralyzed from the chest down. As an engineer, with a brain calibrated to see problems and solve them, in those dark months in the hospital after his son’s accident, Martin saw problems everywhere he looked.

“It was so eye-opening to me that I no longer could work on anything else,” says Martin, who dragged a then-rare, uber-expensive, shipped-from-Switzerland low air loss mattress into Liam’s hospital room on a Sunday—“because you can do anything in a hospital on a Sunday”—to ward off pressure ulcers, the deadly condition that killed Christopher Reeve. (He says the hospital has since switched to these mattresses, although he takes no credit for it).

Martin then left the competitive field of combustion for assistive technology and co-founded the UW-CREATe lab, or the Center for Rehabilitation Engineering and Assistive Technology, where his students went on to design innovations like the Funicular, a platform that uses a chain hoist and rollers to drive wheelchairs up stairs. And in 2013 he left UW to start his own design firm, with chief business development officer Jim Guither, and chief operations officer Liam—who not only managed to graduate high school with his class after his accident, but went on to earn a UW–Madison bachelor’s degree.



Inspired innovation: Jay Martin (left) rigged his hangar so it can lift son Liam (center) up to his plane. The space also serves as a lab for Martin Product Design, where James Guither (right) also works.

One of the most promising products in the one-hundred-plus Martin Product Design portfolio is a sort-of garden-hose-reel device that solves the problem of piles of jumbled hospital cords. Because while working in combustion, particularly as it relates to advancements in auto technology, Martin had to find slivers of subtle, highly specialized problems to solve if he wanted to make any kind of difference. “But when I looked at the field of assistive technology, there was nobody. And there were so many problems. I mean, to find a good problem, all you had to do was walk out the door and there it was,” he says. “And when I say walk out the door, there’s almost no building in Madison that has the door buttons in the right place.”

Just as Buinevicius is clear that Rowheels is about innovation and Liam is clear he doesn’t want to be some sort of inspirational wheelchair poster boy, Martin insists that he’s doing what he loves and that he’s found a field where “the sky’s the limit.” Guither points out Liam’s \$200 water bottle, one he’s had to modify and the only one like it available on the market in a country where the rest of us puzzle between hundreds of styles, colors and materials, and breaks it down in capitalist terms: “There’s a tremendous unmet market need here,” says Guither, before turning the conversation in a more philosophical direction. “We know we can do so much better.”

Like so many other components of Universal Design, Martin’s user-centered innovations are not only good business, they’re better for everyone. That hospital cord device, for example, has real implications for patient care professionals, for one, but also for actual garden hoses. The hands-free devices so many of us use in our cars started with assistive technology. That perennial wedding registry item, the Cuisinart food processor, was invented to accommodate people with physical limitations. When we’re pushing our babies in strollers down the sidewalk, we’re shocked when we can’t find a curb cut. When we press the elevator button over here and the doors open way down there, we’ve got time to wander in and get settled—that pause was designed to accommodate people with disabilities. Just like the “door buttons” Martin mentioned, those squares we palm-slap to open doors when we’re carrying groceries or backpacks or kids. We’re benefiting all day long from assistive technology, even as the multitude of remaining problems stay invisible to us. And the potential for economic growth and groundbreaking innovation in the field of assistive technology is staggeringly big.

“It’s funny because in my former life, if you work in combustion you’re associated with automobiles, and our automobiles are amazing devices right now. If they don’t work perfectly, everybody’s totally upset,” says Martin. “In the world of disability, it’s so different. If it works at all, you’re happy.”

Access Ability

Two local groups help enhance quality of life for people with disabilities



Before chaperoning the 2001 middle school skiing field trip that left her spinal cord completely severed, Monica Kamal didn’t think a whole lot about accessibility or adaptive recreation. She had some awareness, sure, but not the brutally inescapable kind that comes only when it’s you, waking up to your new normal, in a city that has become utterly unrecognizable—and inaccessible—overnight. Kamal had never really thought about how easy it was to hike a state park trail or slip a kayak into smooth, cool waters, or even hop in the car and run to parent-teacher conferences. Today, she thinks of little else.

“Because it’s Madison, you think it’s this place of strong resources,” says Kamal, who has since founded Madison Spinal Cord Injury & Issues, or Madison SCI, an all-inclusive, nonprofit awareness, information and support group for people with disabilities. “And it has strong resources for children with disabilities, but if you’re over eighteen and under fifty-five, there are hardly any resources there for you.”

Today, Madison SCI, celebrating its tenth anniversary, strives to be one of those resources. What started as a support group, after Kamal couldn’t find one to join herself, has evolved into a chapter of the United Spinal Association with seventy to eighty local members—and not just people with spinal cord injuries.

Anyone who has mobility impairments is welcome, including those with conditions such as multiple sclerosis and cerebral palsy and—perhaps most notably—able-bodied family members. That’s a big reason Madison SCI exists—to help people with disabilities engage in the same activities and opportunities their loved ones enjoy.

The group facilitates meet-ups at the Memorial Union and Concerts on the Square, hosts monthly topic meetings featuring visits from groups like the UW–Whitewater basketball team and Madison Curling Club and organizes adaptive cycling and kayaking outings with the help of student volunteers from the University of Wisconsin Physical Therapy program.

“We just want people out in the community and showing what is possible,” says Tina McFadden, Madison SCI treasurer and member coordinator. “Because it is scary when you’re first injured and you don’t think you can do anything. You have two lives, your life before and your life after. By

joining Madison SCI, I feel like my life is a lot fuller.”

McFadden was struck by a boat while waterskiing on Lake Waubesa, causing a T12 spinal cord injury that left some feeling in her toes and slight muscle movement in her legs.

It was 1990, practically lifetimes ago in the disability rights movement. There were no curb cuts, no adaptive kayak outings. The Americans with Disabilities Act had just passed. McFadden was an active and social bank teller just starting a real estate career who loved to go dancing with her girlfriends. She was twenty-five years old.

“There was no support, there was just nothing,” says McFadden, who exercised five to six hours a day in the months and years after her accident to regain what movement she could. Today she can pull herself to standing.

“I was at the hospital for three and a half months and I cried when I left, because at least there, it’s a structure. You get up, you get therapy, you have art class, you have people to talk to. You come home, there’s nothing. So it’s very scary.”

Before joining Madison SCI, McFadden had no other friends in wheelchairs. She didn’t know about the Adapted Fitness program at the UW Natatorium she frequents today, and, despite her healthy and active lifestyle, had never tried hand biking or kayaking or any of the other adaptive recreational hobbies she and her able-bodied partner (Rick, her boyfriend since 1987, before her accident) now regularly do together.

“We want Madison to be as accessible as possible for people to do as much as they want,” says McFadden. “We’re just trying to show that you’re only as limited as you think you are. So if you want to try to do something, there is a way of doing it.”

One of the group’s key goals is to acquire adaptive equipment for free use by its members, because such equipment can be highly cost prohibitive (an adaptive hand bicycle, for example, runs \$3,000 to 4,000). Just this year, Madison SCI received a \$4,293 grant from the Christopher & Dana Reeve Foundation to purchase an adaptive tandem kayak, allowing for an able-bodied person and a person with mobility issues to get out on the water together.

Kamal was especially touched by an able-bodied member who, after an adaptive kayak outing with his sister who has multiple sclerosis, said it was the first time he saw her not as a wheelchair user, but just as his sister.

“So that was pretty special,” says Kamal, who also co-founded Access Ability Wisconsin to help people with disabilities access the state’s rich natural resources through activities such as adaptive hunting and fishing. The Dane County group just raised enough funds to acquire its first all-terrain wheelchair.

“What I’d like Wisconsinites to know is that there are opportunities that are naturally given to people that everybody wants to do, whether they’re a wheelchair user or not,” says Kamal. “And so be thankful about the gifts and opportunities you’re given. And if you’re able to help others get out and experience that, that decreases depression, increases opportunities and, because of that, helps their health and our health care system.”

Maggie Ginsberg is a contributing editor for Madison Magazine. Special thanks to Alicia Boehme,

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