

What

Matters

RELATIONSHIPS

ACCOMPLISHMENTS

FREEDOM

COMMUNITY

NEW EXPERIENCES

EXPECTATIONS

OPPORTUNITIES

CHOICES

PURPOSE



What matters? That our days be spent with purpose. This is true for all of us.

To make that a reality for more people with disabilities – including those with the most significant support needs – services are changing to help people lead the lives they want. Ensuring people with disabilities have opportunities to work and spend their days in other meaningful ways, alongside people without disabilities, is one of the ways change is happening.

What Matters tells nine stories of people showing what matters in their days: having choices, overcoming challenges, enjoying enriching relationships, engaging in meaningful work, exploring interests, and having flexible supports, to name a few.

These nine individuals, their families, providers, support staff, and employers share their stories of struggle and success in creating meaningful days, despite varying abilities and disabilities. ***What Matters*** shows what that can look like.



Relationships

Lisa, 35, is a spirited, capable woman who has landed jobs in food service and cleaning, and yet would frequently lose those jobs shortly after getting hired. Lisa has some mental health challenges and an intellectual disability, and she has struggled with the deaths of both her mother and sister. Her support staff believed she was self-sabotaging because she wasn't motivated to work.

"At first we thought, maybe, when she felt better, we would find her a lasting job," says Jamie, the provider agency's director of outreach. "But we're all motivated by something, and we, as Lisa's team, needed to figure out what that was."

So Lisa's entire support team - her job coach, job developer, director of outreach, and case manager - met with Lisa to figure out what was important to her. They gave Lisa a "Charting the Lifecourse" questionnaire to explore

what kinds of experiences she liked, and what mattered to her. "This was life changing," says Jamie.

"We discovered that Lisa craved meaningful relationships and she liked helping people. She's a natural caregiver, and we found a job that fit her needs."

Lisa now works in a school for children with disabilities in Harford County, where she helps students who cannot feed themselves. She loves her work and is engaged with the children, paying close attention to their needs and taking responsibility to meet them. "I love the kids," says Lisa. "They make me happy. It's fun working there."

Lisa adds that her job is so fulfilling she is encouraging her boyfriend to get a job, too. She is excited about saving money so they can move in together. For now, she spends weekends with him and his family, and loves going to fairs and riding the ferris wheel.

Lisa was not motivated by money alone. She needed work and goals that felt good to her. Now she never misses a day of work, and she even trains others to help children at the school. According to her case manager, Madicella, "Lisa has developed strong relationships with the students and is genuinely concerned about them. She's able to give back to her community and is thriving being employed again."

Jamie adds, "We had to stop making assumptions about what Lisa should do and learn to listen to her. Finding work that fit what matters to Lisa turned her life around. She is now 100 percent successful in her job."



Accomplishments

Cherish hired **James** three years ago when he applied to work at the Kentucky Fried Chicken (KFC) restaurant she managed in St. Mary's County. "Everybody has some type of learning curve," she says. "We just had to figure out what works for him."

At first, James, who has an intellectual disability, worked as a cook, but one time he burned some chicken and was reprimanded so sternly by a supervisor that he didn't want to cook anymore. "That supervisor is no longer working for us," notes Cherish. "James is already hard on himself when he makes a mistake. And we all make mistakes. I can teach anybody anything, but if they don't care, it won't matter. James really cares. So two years ago when I moved to a KFC store in Calvert County, I created a new job description for him: Cleaning Captain."

James took pride in his new duties - restocking and organizing supplies,

and cleaning tables, floors, windows, and bathrooms. But bringing him into contact with customers also raised new concerns. When a customer tracked mud on a floor James had just mopped, or scattered trash on a recently cleaned table, James would get frustrated and scold the person.

"James was not used to dealing with the public," Cherish says. "I was worried that this could cause a big conflict." To help James work through any unexpected situations, Cherish "steps outside with him to hear him out. I listen, and we always end with a hug. This has been an opportunity for him to work on his own personal development, and it shows. He has grown so much in these years and has learned much better self control in these challenging moments."

Learning has worked both ways, with some KFC patrons benefiting from their interactions with James by cleaning up after themselves

after finishing their meals. "It's amazing the impact James has on some customers," says Cherish. "He wakes up their awareness. Customers ask about him when he's not here."

James works at KFC three days a week with his job coach, who also drives him to work. Additionally, he volunteers for Meal on Wheels, and has a passion for drawing and music. But he says work is the favorite part of his week: **"I love working. It makes my whole day to come to work. And it's important to me to make my own money that makes my life better."**

His enthusiasm is evident in his energy and commitment as he bustles about the restaurant cleaning and organizing. Occasionally, he and Cherish break into a spontaneous dance to the in-store music. His only complaint: "I'd like to work four days instead of three."



Freedom

Donna B. and Donna R. have known each other for 31 years. Born 54 years ago with cerebral palsy, Donna B. has attended the same day program in rural Charles County since she was a young adult. For almost as long, Donna R. has been executive director of the agency, which in recent years has changed, supporting people in the community instead of only at the day program inside the center.

Donna R. explains that figuring out how to enact that change has required some creative thinking by her and her staff, as well as courage from the people that have been supported by the agency a long time. As she points out, “Sometimes the community is not so friendly when they see people with significant disabilities.”

But despite some initial fears, Donna B. wanted to try spending her days out in the world, rather than only at the center. “I didn’t know if I would like it,” she says, “but I wanted to try.”

There have been challenges. People have sometimes stared at her.

Prospective employers made quick assumptions about Donna’s limitations, both real and perceived. She tried to work at an animal shelter, but its doors were too narrow for her wheelchair. Later, she landed a volunteer position two days a week at a residential rehab center, but had to go all the way home for bathroom breaks because its bathroom was inaccessible to her. Noting Donna’s dedication – and after giving the situation some thought – the facility eventually agreed to allow her to keep a hooyer lift in its bathroom so she could work all day without interruption.

Donna accesses her job with the help of her support person, Tonya, but she doesn’t need any help to connect with her patients. “We talk,” she notes. “They enjoy my company and often tell me they don’t have any family. I am their only visitor for the day. I love helping people who seem to need more help than I do.”

Donna still takes advantage of resources at the agency’s center, such as music therapy, art classes, and

exercising with the quadriciser. But she also goes out into the community every day – shopping, applying for jobs, using the computer at the local library. She is happy about the blending of both worlds, discovering new ways to grow. She taught herself to paint using a headset, and now teaches children at the local child-care center to paint the same way.

Asked if the change has been worth the challenges, Donna is emphatic. “Yes! I’m an outside person. I love having no walls around me and feeling free. It’s not what I do every week, it’s the journey.”

Adds Donna R., “It’s not about perfection. It’s about making her life the same as anybody else’s. Each year we see progress. Donna hopes to be paid for the job she does. Next year, we may see that happen.”

Donna R. and Donna B. agree: “We want acceptance and blending into the community where it’s natural. We aren’t just hanging out; we’re building relationships.”



Community

Born in Baltimore City with lissencephaly, a brain disorder, **Paz**, 24, can't speak or use her arms and legs. She needs assistance to get around in her wheelchair, and with all activities of daily living. Yet from birth she has been included in her community with her peers without disabilities, communicating her preferences by squirming or going to sleep when bored or unhappy, and smiling alertly when life feels good.

Paz's services are self-directed and overseen by her parents, Leslie and Russ, who interviewed several people before choosing Nahkita to be Paz's support person. For additional hours of support in the home, Leslie and Russ brought in Pearl, Paz's former elementary school aide. With Nahkita and Pearl's support, Paz has thrived. Her days out in the community with Nahkita are spent awake, engaged, calm, and smiling. Her mother reports that she makes up for it by sleeping a lot at home on weekends.

One of Leslie's operating principles is the concept of "dignity of risk." She explains: "People with disabilities have the same right to risk as the rest of us. The same right to smell the roses and maybe get scratched by a thorn. With lissencephaly, Paz's health could be considered fragile. But I'm not going to keep Paz in a bubble."

So Paz's weekdays with Nahkita are busy. They might go to Belvedere Square for music and lunch, or to the movies, or roll through a breezy park or down city sidewalks teaming with life. They've been to Annapolis to advocate, to music events and museums, and to Dave & Buster's because Paz enjoys the arcade lights and sounds. They participate in Athletes Serving Athletes and go rollerskating. Sometimes, they visit the principal, teachers, and students at Paz's old school, or attend a sporting event. Often, she is included at one of Nahkita's large family gatherings, or watches Nahkita's son at one of his basketball games.

Paz is so embraced by the family that Nahkita's grandmother fills in if Nahkita needs a day off.

Paz and Nahkita volunteer regularly at the recreation center in Sandtown-Winchester, handing out snacks to kids after watching them race around the gym. The children appreciate Paz, hugging her and laughing with her, their hands covered with cupcake crumbs. She smiles and turns her head toward them, tracking them quietly with her eyes. Her presence impacts them, too.

"Paz draws people to her," says Leslie. "It's been that way since she was a baby. The more you get to know her, the more you get from her."



New Experiences

Lorraine, 47, lived with her mother for the first 33 years of her life. Born with an intellectual disability, Lorraine now reflects, "My mother did everything for me and taught me all I knew." And when her mother died 14 years ago, Lorraine says, "I was lost." She experienced huge changes, including moving to Maryland to live with her sister, and looking for work with the support of a provider agency in Prince George's County.

Fortunately, her sister, who at the time had a 3-year-old daughter, soon gave birth to another baby girl, and Lorraine enjoyed taking care of the children. Lorraine had always loved children, and she was able to be helpful to her sister and nieces.

So when she was offered a volunteer position caring for toddlers in a childcare program, she was both nervous and excited. "Working with children was a dream come true," she explains, "but I wasn't sure a job would happen for me."

At first, her provider agency supported her with daily job coaching and transportation. After six months, she began earning a salary for her work. Now, 11 years later, Lorraine remains a trusted employee of the childcare center. She works 25 hours a week, and while she still depends on support for transportation each workday, her job coaching has faded to weekly.

Lorraine's employer raves: "She is an exceptionally committed, conscientious employee. She loves the children. She really works when she's here, giving the toddlers her complete attention. She is always engaged and looking out for them. And people love and value her."

"I fell in love with my job," Lorraine says. "When I got my first paycheck, I was so proud I wanted to hang it on my wall."

Each weekday after work, Lorraine receives some personal supports to pursue her interests and try new experiences. She goes belly dancing

and bowling, and taps into her creative side by making and selling her own flower arrangements and wreaths.

Lorraine notes that she learned to be brave after her mother's death. "I learned that being brave doesn't mean you always have to do well or win. But being brave means that you have to try."



Expectations

When **Evan** was diagnosed with autism as a toddler in 1995, his mother, Andrea, recalls his doctor's grim words: "Go home and mourn the loss of a normal child." Fortunately, Andrea then met the director of her local Anne Arundel County Public Schools (AACPS) early intervention program, who offered another memorable piece of advice: "You'll have to invent Evan's future."

Fast forward 20 years full of creative and supportive teachers and therapists, and "Evan has become the man he was meant to be," says Andrea. "He's smart, funny, talented, and a hard worker." He still has a significant disability – a language-processing disorder that makes verbal communication difficult – but thanks to assistance from his job coach and a personal support aide, he is enjoying a full life.

Evan works 32 hours a week at the AACPS early intervention resource

center. He delivers mail, does data entry on the computer, and several times a day takes a break to play classical music on the piano in the lobby, entertaining himself and others. Music is Evan's passion, and he is studying music composition at Anne Arundel Community College, where he also performs with a brass ensemble.

Evan's job coach accompanies him to his job, and his personal support aide helps him at school. **"I'm very excited to have this job where people rely on me," Evan notes. "I want to do a great job more than anything."**

His employer, Wes, director of the resource center, says, "When we hired Evan, it was with the expectation that he be a significant contributing member of our team. I was confident that combining high expectations along with job duties selected in areas of his strengths

would create success. Some staff initially expressed concern that he might be a distraction, but he has proven to be a positive influence and an example of what's possible when people are given the chance to shine. Evan demonstrates daily that he is capable both personally and professionally."

Evan has become a valued member of his community, paying forward the trust placed in him. As Wes points out, "Evan gives hope to families of newly diagnosed infants and toddlers when they walk in the door for the first time and meet him."



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Opportunities

Sherrae loves to sing and build connections with people around music. Each week, she plays piano in the lobby of Kennedy Krieger Institute, where passersby pause to sing with her or dance. If someone has a favorite song, Sherrae will play it when she spots them entering the building, always remembering to connect the right song to the right person.

Her mother, Vanessa, says, “To see her singing happily today, you’d never know what behavior challenges she has had.”

Born with an intellectual disability and autism, Sherrae struggles with verbal communication, but her behaviors can speak louder than words. Now 40 years old, she has experienced some day and residential programs in the past that did not work for her. During those years, her aggressive and self-injurious behaviors were troubling. Vanessa notes that her daughter stopped learning altogether and “spent her days just sitting in a group at the center doing nothing.” That changed three years ago when she

found a new day program with more intensive supports that made all the difference.

Airyanna has known Sherrae for the past five years, working first as a support person in her Baltimore County supported living residence, and, later on, at her day program. She was soon promoted but still sees Sherrae daily.

“I see such a positive change in Sherrae,” says Airyanna. “She’s speaking more, gaining some communication skills to advocate for herself. She’s a much happier person.”

Vanessa points out that Sherrae is growing and learning, developing new abilities: “When she comes home on weekends, I notice her trying to clean up in the kitchen and help with the laundry.”

The difference, Airyanna and Vanessa agree, has been more educated and dedicated support staff who have higher expectations for Sherrae.

They have enabled more effective communication with Sherrae, creating real opportunities for her to engage with people in ways she enjoys and allowing her to build her day around her own interests and abilities.

Besides playing piano, Sherrae spends time practicing math, reading, and communication skills within a small group. And every afternoon she’s out in the community, often at the YMCA, where she likes using the treadmill and the pool and engaging more people with song. Also, she loves to shop for CDs at the Goodwill, or peruse and listen to new music at a local record store. On weekends, she enjoys going to church with her mother, and out to concerts with her sister. Fewer behaviors means more access to the community and more experiences that make her happy.

When asked what she loves most about her day, Sherrae says, “music.” She is excited that she will be singing the song “Old Friend” at Airyanna’s wedding in the fall.



Choices

Dom, 25, works three and one-half hours weekday mornings at his neighborhood bakery, and sometimes chooses to work extra on weekends. He likes the work and the money he earns.

Just four years ago, Dom, born with an intellectual disability, spent his days in a sheltered workshop. His job coach, Erin, explains, “We have our own unique challenges in Dorchester County, being a poor, rural area with low employment opportunities. Families used to the sheltered workshops didn’t want their adult children out in a world they feared was not safe or friendly. Some said, ‘My son can’t work.’ It’s not just about work, it’s about supporting them to do what they want. Dom wanted to work. Despite high unemployment, everybody knows everybody in this rural community, and we’ve found our small local businesses can do natural supports really well.”

The neighborhood bakery was looking for a dishwasher — a hard-working, organized, friendly, and reliable

employee. Erin asked Dom, “Can you do that?” His answer: “Absolutely.”

Erin supported him with job coaching initially, but that need faded as Dom’s confidence increased, and he now works independently, with Erin driving him to and from work.

“He is often the only dishwasher on the shift,” notes Erin. “He clocks in and out independently, manages his own time and breaks, and has earned the respect and friendship of his coworkers. This is a small local bakery, not a franchise or chain. He is a fully included member of his community, and he’s proud of the work he does.”

Erin adds that Dom’s boss at the bakery agrees with her assessment that “Dom is an excellent employee, a hard worker who never misses a day. He even chooses to work the days around Thanksgiving and snow days.”

Dom has a case manager who helps him keep track of his earned income and government benefits to ensure that all his needs are met.

After work, Erin drives Dom to meet up with his friends for lunch. They also receive support, and together they talk about what interests them. Personalities emerge during this discussion, and they make choices about what to do during the afternoon. Sometimes, Dom volunteers at an animal shelter, and he loves going to the YMCA to play basketball with his friends Isaac, Ryan, Nick, and Aaron. The men are often joined in a game by other community members.

On this afternoon at the Y, Dom dribbles his ball in the sun-streaked gym, passing it under one leg and then catching it. The men laugh and take turns leaping high to make shots, enjoying each other’s buoyant energy.

When asked which he loves best, working at the bakery or playing basketball, Dom pauses thoughtfully, ball in hand, to consider. Then he breaks into a wide grin and says, “both.”



Purpose

Dustin has an entrepreneurial spirit, and his passion is weaving. Born with cerebral palsy that impacts his physical and cognitive abilities, he likes to weave by hand, even though he can use only one of his, because, as he explains, **“This makes for character and integrity in the product, and that is my purpose, along with building a business. It feels good to have a purpose.”**

Four days a week for six hours a day, he participates in a community day services program with three other adults. During that time, the group volunteers at different places in their rural Washington County community, while also visiting parks and libraries, and working on life skills activities.

Dustin, 30, says he can use that time to work on his weaving, which he carries with him. He remembers a time when his day program and work were all center based, and notes that, although he doesn't like change, he now prefers going out into the community each day because of

the broader variety of people with whom he engages: “I now meet more different people who I can relate to. I like the social aspect of being in the community.”

Some days, Dustin goes to his job at the Marketplace, an antiques and curiosity shop in Sharpsburg, where he opens the store and runs the cash register, dealing with a variety of customers and consignors. He also sells his woven rugs and placemats at the shop.

“Dustin does a good job of understanding people's different abilities and moods,” says his program manager, Scott, making him an asset to the business. Standing by to help is his job coach, who Dustin says is “more of a facilitator, helpful when I need him but not in the way.”

Some of his community hours are spent serving on various committees. For example, he is vice president of the Legends, a self-advocacy group for which he organizes fundraisers such as bake sales and car washes,

with the proceeds going to the Humane Society. And he attends meetings of the Weavers Roundtable, during which he learns about weaving techniques and materials. He also has a support person to help him go out one or two evenings a week to shop for home needs. “My favorite thing is to use that time to hang out and talk with my best friend, Tommy,” says Dustin.

Recently, Dustin moved out of his parents' homes into his own apartment. He admits that the change was hard at first. “It was overwhelming moving in there and knowing the things I could no longer count on: meals being made for me, easy social interaction,” he explains. “There's homeyness and loneliness. The homeyness, how I make it my own, is important, but the loneliness can suddenly bite me. I'm getting used to the homey factor plus being alone.

“It was my idea to move out,” he adds. “Nobody really wants to live with their parents forever.”

Thank you to the individuals and families who generously shared what matters to them.

Lisa Ruley

Harford County

Paz Margolis

Baltimore City

Sherrae Sydnor

Baltimore County

James Gregory Cutchember

St. Mary's County

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