

# New Horizons

Housing That Supports Independence



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## ***New TV Series Spotlights Entrepreneurs With Disabilities***

By Shaun Heasley | Reprinted from August 16, 2021 DisAbility Scoop

The production company behind reality shows like “Keeping up with the Kardashians” and “Born This Way” is set to debut a new series following four entrepreneurs with various disabilities.

The documentary series “Born For Business” will premiere with 10 episodes on NBC Universal’s streaming service Peacock later this month.

The show focuses on the ups and downs of running a small business — all amid the challenges posed by the COVID-19 pandemic — for individuals with disabilities.

“For oo long, people with disabilities have been shut out of the workplace,” said Jon Murray of Bunim/Murray Productions, which is producing the new series. “With ‘Born For Business,’ we are showing how people with disabilities have long been using entrepreneurship to create an economic livelihood for themselves.”

Collette Divitto, a baker with Down syndrome who is featured on the show, talks about how no one would hire her after she finished college. But now her business, Colletley’s Cookies, employs other people with disabilities has sold more than 300,000 cookies to date.

Other entrepreneurs on the series include Qiana Allen, who has lupus and owns one of the nation’s top plus-sized clothing stores, Chris Triebes who has spinal muscular atrophy and runs a concert production company in addition to two venues and a music festival ticket service and Lexi Zanghi who has anxiety and operates a fashion brand that’s set to open its first location.

“Born For Business” is produced by Shopify Studios and Bunim/Murray Productions, the creators of the Emmy-winning series “Born This Way,” which followed a group of young adults with Down syndrome. The company is a mainstay in the world of reality television with credits including “The Real World” and several shows featuring members of the Kardashian family.

“Born For Business” will be available to stream on Peacock starting Aug. 23.



Collette Divitto, who has Down syndrome and runs Colletley's Cookies, is featured on "Born For Business." (Shopify Studios)

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# **“My Two Cents”**

By Tracee Battis, Executive Director



## *Project Freedom's Unsung Hero*

Mike Mushak was one of the founding members of what is now known as Project Freedom. Mike recently passed at the young age of 94. He served his country during World War II.

As the story goes, Mike working side by side with Norm and many other dedicated volunteers, was instrumental in those early days ensuring that Norm's vision was realized that people with disabilities be able to live independently and follow their dreams. And now, there are 625 barrier free affordable units in five different counties in the State, and the dream continues.

Mike was a passionate and dedicated volunteer to Project Freedom for over 30 years. He served on Project Freedom's Board of Trustees for many years as the Board Treasurer and stretched those limited dollars to ensure our success.

Mike is one of Project Freedom's Unsung Heroes. We express our sincere appreciation for his contributions, which together with other unsung heroes, are responsible for building the foundation of Project Freedom. His obituary reads, "His integrity and devoted service to God, family, and community is his legacy." We could not agree more and are honored to have known him.

## From Norman's Desk

This month marks 20 years since the attacks of September 11<sup>th</sup>. It is also National Preparedness Month is recognized each September to promote family and community disaster and emergency planning now and throughout the year. The 2021 theme is **"Prepare to Protect. Preparing for disasters is protecting everyone you love."**

For many, the memory of that awful September day in 2001 is fading, but my memories are still vivid down to my shirt and tie. The day started out so bright, beautiful, and refreshing, but it ended so dark and frightening. The feeling of anger and uncertainty spread around us like a cloaking fog.

Every year since the attacks, I choose to pay tribute to the three elements that create my memory of that day. First, I honor the life of my friend and colleague Colleen Fraser who died on Flight 93 with those other selfless heroes who may have saved the Capitol or the White House and thousands of other lives. Colleen was a fighter, and she was in good company that morning fighting to take back that plane.

Second, I remember the lives of the 343 FDNY firefighters who died that day. Most knew going into those buildings that some of them would not come out alive. They knew this instinctively by virtue of their experience and profession. They still went in with police officers and EMS personnel to save those who could not save themselves. They went in to save people with disabilities.

And, yes, thirdly, I remember those people with disabilities who died that day in those towers. I was not watching the horror on television that morning. I had a meeting at 10:00, and during that meeting I spoke of Colleen and wanting to connect her with someone. Later, someone told me of the collapse. My very first thought was that many firefighters had just died; my immediate second thought was that many people with disabilities had died as well.

This year I again pay tribute to the doctors, nurses, medical support staff, direct care staff, and first responders who put their lives on the line trying to save others from COVID-19. They are continuing ran toward danger to help other, and many paid with their health or their lives.

How many people with disabilities died that morning in September may never be known. We do know that the corporations and government agencies housed in those towers hired people with disabilities. We do know that some people with disabilities made it out because they had a plan, their company had a plan, or some colleague or friend took the initiative to get them out. We do know that others stayed behind not wanting to burden friends, not wanting to get in the way, or just having unwavering faith that the FDNY would get to them. We also know that loyal friends stayed behind with them. We know that some people with disabilities who stayed were rescued but many died with their rescuers.

In the same vein, how many people with disabilities have died from COVID-19 may never be accurately known. We do know that over 25% of the COVID-19 deaths occurred in nursing homes where many people with disabilities are forced to live. We do know that people with disabilities living in the community have been isolated by the lack of community-based direct support workers. We do know that the government is not tracking the deaths of people with disabilities as a COVID-19 statistic.

Every victim of these national tragedies needs to be remembered and honored. I feel a personal duty to honor Colleen, The 343, and those almost nameless people with disabilities who stayed behind.

As I say each year, let us all remember the victims and the heroes of September 11, 2001, by getting prepared and staying prepared. You never know how a bright, beautiful, refreshing day may quickly turn very dark.

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# ***Unique Farm, Neighborhood Designed With Inclusion In Mind***

By Hannah Hagemann, reprinted from the Santa Cruz Sentinel/TNS | August 24, 2021

SANTA CRUZ, Calif. — Tucked away from the hustle and bustle of Highway 9, just yards away from Pogonip, is the vibrant Common Roots Farm. There, farmers water ruby strawberries, hearty kale and mesmerizing dahlias. Twenty different food crops and 30 flower varieties are tended to by volunteers and farm staff.

Many of those community members who work the farm are people who live with intellectual and developmental disabilities. Some also live with physical disabilities. “We’re like any farm you’d find and not a ‘special needs farm,’” explained Farm Manager Nina Vukicevic. “This place is for people with and without disabilities, the beauty of it is you’re offered the same opportunities so far as they make sense for you and your abilities.”

Thomas Kernot, who has autism and epilepsy, has been volunteering at the farm for a few years. On a recent morning he watered row crops. When asked how he was, Kernot replied “happy.” “Thomas loves to come here,” Kernot’s support staff Cecilia Vacquez said. “A few years ago, he didn’t like to be around a lot of other people ... he would be so nervous and now he interacts a lot more.”

Five years ago, Common Roots Farm in Santa Cruz was filled with waist high weeds. The property — on Golf Course Drive — had been historically farmed for a century, but not in more recent years. The farm offers weekly shares of vegetables, produce, eggs and flowers through a community-supported agriculture program, or CSA. “My big slogan is no pity produce here — my focus is growing the highest quality products we can,” said Heidi Cartan, executive director of Common Roots Farm. “I want people to buy because we have great quality stuff.” Cartan founded the farm with her husband. Their adult son, Noah, has cerebral palsy.

The couple wanted to open up a space where the disability community could positively contribute and find purpose in the environmental sphere. “One of the big issues of the day is climate change and environmental stewardship,” Cartan said. “I didn’t see a place for my son to fit into solving that problem and this is a place where people with disabilities can have a leadership role and stewardship in addressing those things.”

The farm, which doesn’t use herbicides or pesticides, relies on its staff and volunteers to keep it going. “There’s so much work that has to happen on a farm every day to keep it humming and these are places where people can contribute — not in token ways — but in genuine ways,” Cartan said.

## **Looking to future**

Common Roots has a few projects in the pipeline to expand access and produce offerings. In September the farm will unveil its upgraded 3,000-square-foot Seed to Salad accessible garden and farm path.

Cartan said the projects are crucial for community members with disabilities. The perimeter path, which will run along the entire farm, will allow people who use mobility equipment — such as a wheelchair — to more deeply experience Common Roots. The expanded accessible garden will offer people opportunities to work the farm beyond row crops. Vegetables will be planted in raised and roll under garden beds.

The COVID-19 pandemic hit the farm particularly hard. Common Roots previously worked with local restaurateurs and Santa Cruz Shakespeare, as well as ran a farm stand, but those endeavors had to be paused. Cartan hopes to reinstitute those programs in the coming year.

## **Farm expanding**

The farm community is also expanding. Next door to Common Roots, Coastal Haven Families LLC — an adjoining pocket neighborhood that will offer homes to people with intellectual and developmental disabilities — is under construction. The neighborhood will boast 11 homes. Cartan’s son Noah will also be a community member at Coastal Haven. “Noah is very social, and we wanted him to live with other people in a community, and we really felt like we could do something with other families that would be much better than anything any individual family could do alone,” Cartan said.

Future residents such as Thomas Kernot, may choose to also participate in farm work next door. Move in is slated for Sept. 1. Beyond an organic farm, Common Roots is blooming into a thriving community. “We’ve been so busy building a startup and now we’re going to flip the switch and have people use it,” Cartan said.

## ***Families Struggle With State Agencies To Get Home-Based Care***

By Anita Wadhvani, reprinted from the Tennessee Lookout | August 17, 2021

MOHAWK, Tenn. — Drama Bryant's entire life has revolved around caring for her little brother, Jay, who — at 32 years old — requires 24/7 assistance as a result of congenital conditions that leave him unable to eat, bathe, go to the bathroom, speak or walk unassisted.

His intellectual and physical disabilities qualify him for a program operated by the Tennessee Department of Intellectual and Developmental Disabilities that is supposed to provide Jay with 337 hours of professional care each month in the home he shares with his 69-year-old mom — who herself has a disability and early symptoms of dementia.

Jay Bryant is enrolled in a program through the Department of Intellectual and Developmental Disabilities, which provides home-based services. The services are paid for by Tennessee's Medicaid program, TennCare, which provides similar services to people without intellectual disabilities.

The two programs offer differing pay rates for comparable work. DIDD's program pays lower wages to in-home caregivers for people with intellectual disabilities than TennCare pays for caregivers providing the same services to other home-bound individuals — those with physical illnesses or disabilities, for example.

In-home care can encompass a variety of job titles including skilled nurse, personal assistants, home health workers, physical therapy, housekeeping and other therapeutic caregivers. The purpose of the programs is to keep individuals who would otherwise qualify for a nursing home at home with visiting staff caring for everyday needs.

State lawmakers this year approved a raise for support workers caring for people with intellectual disabilities at home — from \$11 per hour to \$12.50, bringing their pay in line with the rates paid to TennCare workers providing similar care.

But the disparity in pay rates for all other in-home workers remains.

Take the example of a respite worker, who can relieve regular in-home staff or family members. TennCare pays managed care organizations who hire the workers a rate of \$4.03 per quarter hour, according to the agency's most recent rate scale. Agencies who hire workers to provide similar respite services to people enrolled in the DIDD program are paid \$3.91. The rates represent the amount paid to the middlemen — nonprofit agencies or managed care

Other pay rates are difficult to compare directly given differing types of pay scales provided by each agency. Vanessa Zapata, a staff attorney with the Tennessee Justice Center, said attorneys representing people enrolled in both programs have been unable to get hard ranges or pay scales.

In July, Zapata and attorneys with the Tennessee Justice Center filed suit in federal court against the state alleging it has discriminated against people with intellectual disabilities in violation of the Americans with Disabilities Act and the Medicaid Act.

“The State ... fails to provide in-home care required to meet the Plaintiff’s acknowledged needs,” the lawsuit said. “As a result, the Plaintiffs repeatedly experience gaps in their care, causing preventable suffering, harm to their health and heightened risk of involuntary institutionalization.”

“The State’s chronic failure to meet the Plaintiff’s care needs is due to the State’s longstanding insistence on paying lower rates for home care services for people in the DIDD Waiver than TennCare pays for identical services provided to all other TennCare enrollees.”

A spokeswoman for the Department of Intellectual and Developmental Disabilities declined to respond to questions about pay disparities or how many individuals enrolled in DIDD’s in-home care programs lacked adequate staffing, citing the ongoing lawsuit.

The agency uses social media to highlight the benefits of becoming a direct care worker, said Cara Kumari, the spokeswoman. Kumari noted that pay rates are out of the agency’s hands. Each agency that contracts with DIDD to provide care makes its own hiring, wage and benefit decisions, she said.

The suit has thus far led to a partial victory for the Bryants, who are named in the suit.

Attorneys have agreed to an order in the case that requires state agencies to ensure Jay and four other plaintiffs immediately get the in-home care for which they have already been approved.

Drama Bryant, who hopes she will still get the time to pursue her career in web design, said that making sacrifices for her brother is a no-brainer. She has set her career aside for now, and lives in a mobile trailer behind her mother’s home so she can be nearby. She isn’t married and doesn’t have children — not, she said, because they can’t find caregivers, but because “Jay just wouldn’t understand if I did.”



# Labor Day 2021

## ***Why Do We Celebrate Labor Day?***

Labor Day, an annual celebration of workers and their achievements, originated during one of American labor history's most dismal chapters.

In the late 1800s, at the height of the Industrial Revolution in the United States, the average American worked 12-hour days and seven-day weeks in order to eke out a basic living. Despite restrictions in some states, children as young as 5 or 6 toiled in mills, factories and mines across the country, earning a fraction of their adult counterparts' wages.

People of all ages, particularly the very poor and recent immigrants, often faced extremely unsafe working conditions, with insufficient access to fresh air, sanitary facilities and breaks.

As manufacturing increasingly supplanted agriculture as the wellspring of American employment, labor unions, which had first appeared in the late 18th century, grew more prominent and vocal. They began organizing strikes and rallies to protest poor conditions and compel employers to renegotiate hours and pay.

Many of these events turned violent during this period, including the infamous Haymarket Riot of 1886, in which several Chicago policemen and workers were killed. Others gave rise to longstanding traditions: On September 5, 1882, 10,000 workers took unpaid time off to march from City Hall to Union Square in New York City, holding the first Labor Day parade in U.S. history.

The idea of a "workingmen's holiday," celebrated on the first Monday in September, caught on in other industrial centers across the country, and many states passed legislation recognizing it. Congress would not legalize the holiday until 12 years later, when a watershed moment in American labor history brought workers' rights squarely into the public's view. On May 11, 1894, employees of the Pullman Palace Car Company in Chicago went on strike to protest wage cuts and the firing of union representatives.

On June 26, the American Railroad Union, led by Eugene V. Debs, called for a boycott of all Pullman railway cars, crippling railroad traffic nationwide. To break the Pullman strike, the federal government dispatched troops to Chicago, unleashing a wave of riots that resulted in the deaths of more than a dozen workers.