

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SPRING 2019

PEOPLE

WITH

DISABILITIES



**ADVOCATING FOR
COMPETITIVE
EMPLOYMENT**

IN MEMORY OF
ETHAN B. ELLIS

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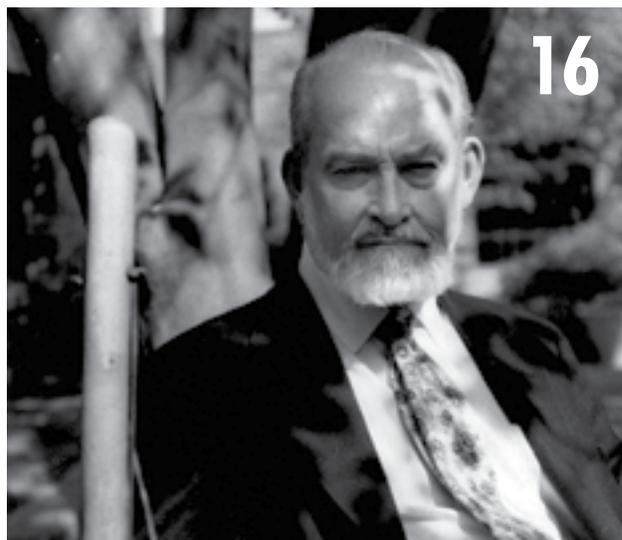
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Ethan B. Ellis

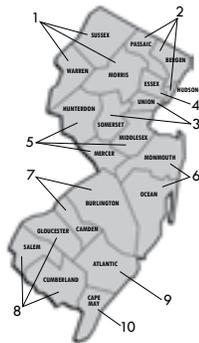
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Advocating for More Employment Opportunities



New Jersey became an ‘Employment First State’ during April 2012, but as a NJCDD Council member put it, “employment first needs to be more than just a slogan.”

In fact, the employment numbers for people with disabilities in New Jersey is not encouraging. According to the Federal Office of Disability Employment Policy and Federal Bureau of Labor Statistics, employment of individuals with disabilities remains disproportionate to those who are not disabled.

According to HealthResearchFunding.org, 82.2 percent of people with developmental disabilities are unemployed. That’s the overall unemployment rate for this population demographic. It means that there are 1.2 million people in the US who can work yet have a barrier in place preventing that from happening.

Workers with a disability were more likely to be employed part time than those without a disability. In 2018, 31 percent of all workers with a disability usually worked part time, compared to 17 percent of those without a disability.

People with developmental disabilities should have access to the full array of opportunities including pre-apprenticeships, apprenticeships, and on the job training to help maximize opportunities and employment outcomes.

The NJCDD maintains employment as a key goal within our five-year plan. In addition to raising awareness about employment in this issue of *People & Families Magazine*, NJCDD continues a three-pronged approach to removing obstacles to gainful employment for people with developmental disabilities.

First, the NJCDD formed a work group to revise our position on employment. We will issue

a revised position statement highlighting our renewed focus.

Second, the Council supports the employment-related efforts of the NJ Developmental Disabilities Advocacy Network (DDAN). We support DDAN’s employment issue paper and recommendations.

Third, the Council will soon publish a request for proposals to support pilot programs using best practices to advance New Jersey’s performance as an Employment First state.

These efforts are being galvanized so that we can continue to put pressure on the system to improve access to competitive employment for those with developmental disabilities who are eager to work.

Unfortunately, history continues to repeat itself when it comes to the low rate of employment among people with developmental disabilities.

Ethan B. Ellis wrote about employment challenges for individuals with disabilities in the December of 1994 issue of *People with Disabilities*. I find it unacceptable that 25 years later we are still engaged in many of the same conversations.

Sadly, Ethan passed away on Friday, March 22 in Piscataway, NJ. He was 85. During his career, he was instrumental in the success of the Americans with Disabilities Act (ADA). He served as Director of the New Jersey Council on Developmental Disabilities when the state closed two developmental centers. His lengthy list of contributions to the field will have a lasting local and national impact.

While we honor Ethan in this issue of *People & Families Magazine*, our unwavering commitment to improving the lives of people with developmental disabilities and their families would be a more fitting tribute to his legacy.

Mercedes Witowsky
Executive Director

New Jersey Council on Developmental Disabilities



Ethan Ellis and Me

“His passion was infectious. It was infused with his personal experiences and the thousands upon thousands of years people with disabilities had been at the mercy of others.”

By Norman Reim

There have been some very good tributes to Ethan since his passing, recapping his career, about his background and his family. The tribute from the Alliance Center for Independence (ACI) posted in several locations is the most thorough. I believe it can still be found at www.adacil.org, [NJDPF Facebook](#), and [ACI Facebook Page](#).

NJ.com and the print edition of the Star Ledger had a very nice feature obituary by Sue Livio. She interviewed Ethan for a number of articles over the years. For those interested in that article it might still be found through a general search or by searching the archives of NJ.com.

So, when the Council asked me to do something about Ethan for its next issue of *People & Families Magazine*, I wondered what I might add. My first thought was to simply add to and reorganize what was already out there what people familiar with his career already knew

about him. I wasn't really inspired along those lines though. After all, however impressive a life was, and his certainly was that, in these more concise testimonials there are only so many ways to cite career accomplishments and biographical details.

Still, I had no better plan so I sat down at the computer and opened up the other obituary materials and sat staring at the screens and my own blank page somewhat unenthusiastically.

I hadn't seen Ethan much in the past few years. As often happens, life carried me along a path that seemed to require much of my localized attention. Although I can't think of what was so consuming now in retrospect. I was in touch with his wife, Janet after the first of this year. We were sort of moving toward setting up a visit. Some health issues came up with me and then Ethan went into the hospital. I thought about going up to see them both while he was still there. Those kinds of visits are always so consumed with the uncomfortable business at hand. I don't think he would have liked that.

His natural element was sitting around with a few friends and confederates and deconstructing the issues of the moment and reconstructing them so they made more sense and plotting out ways to make that new construct more of a reality. I wanted to wait for an opportunity for another one of those, for both of us. That opportunity never came. He contracted a couple of infections and the second one, one of those hospital bugs that make stays in those environments so double-edged, took him before he had a chance to get back home.

If I could have written a different ending it would have had him coming home and getting in at least a few more of those small "ideas" sessions he loved so much before riding off into that proverbial sunset on his scooter, peering up and out

from a slightly bowing posture toward the next horizon and speeding a little too fast for safety; always moving forward.

Remembering his love for those impromptu powwows got me to thinking, though, about the first one we had. I had my hook then.

At the time I was working for the Department of Human Services in the public information office. I knew of Ethan by reputation of course. We all did down at the department. He was that rabble rouser at the (then) DD Council (The New Jersey Developmental Disabilities Council).

I had seen him in passing at those constituency meetings the department had every so often to feel out the timbre of the broader community. And we at OPI (Office of Public Information) had on occasion danced out of a few corners constructed by way of his frank assessments of the state of affairs for people with developmental disabilities, not only in general but specifically at the Council itself. An agency connected with Human Services through a precarious relationship balancing a federal man-

date of independence to oversee the department's performance, while being dependent on DHS for all its administrative needs.

It was called "in but not of," a tantalizing but practically meaningless description. Ethan handled that juggle the way he did most of the others life threw his way—the ones I knew about anyway. He gave the weight to the independent oversight part and let the administrative pieces fall where they may.

But back to that inaugural event between us.

One day Marc Mercer was down at DHS and he and I got to talking about popularity and principle and the vagaries of public employee-dom. I mentioned that I was looking for a change of venue, within state government if I could manage that but, in any case, one that should the seat get hot it would be more in the service of testifying

His natural element was sitting around with a few friends and confederates and deconstructing the issues of the moment and reconstructing them so they made more sense and plotting out ways to make that new construct more of a reality.



During Norman's tenure with the DD Council, he sang and played the guitar during the Partner's graduation day. —November 21, 1999

than proselytizing. He said I should come up the street and talk to Ethan. So I did.

Marc was a good friend of Ethan's. Both fell comfortably under the title iconoclast—individuals whose individuality was a principal, defining characteristic; that is, one of a kind.

Marc was a large lumbering presence. When he walked it was a methodical swaying gait like the giant Tree Ents from the Lord of the Rings. He recited poetry whether the occasion called for it or not; mostly his own but not always. His voice was a baritone rumble. Writing though was his most persuasive communication tool. One Ethan used masterfully.

At the time the Council offices were in an old office building two thirds of a block west on State Street—28 West. I believe it was but don't hold me to the number. You walked through a glass door from the sidewalk and there was a closed in office directly on your left. That was Ethan's. The rest of the desks marched on along the left side—five or

six or so—and there was an office space for Susan Richmond, the Council deputy director. Beyond was the common area, storage and such.

Ethan was in his office. At his direction I hustled in and closed the door. He was puffing away on his pipe and did not want to bother the others on staff. He was sitting in a high-backed swivel chair with rollers, in suit pants, a white shirt buttoned at the neck with a burgundy and gold floral tie. He wore a suit vest opened all the way exposing the gentle roundness of his stomach. There was the characteristic trimmed beard with the pointed goatee, his slicked back thinning brown hair streaked with early greying, and, most arrestingly, those shrewd but playful eyes, like a boy about to propose some future mischief with his mates.

It was amazing how immediately I was drawn into a strategic brainstorming session as if I had already been offered a job and had accepted. I came to learn that was one of a number of classic

Ethanisms. He operated on the assumption that the persuasiveness of his operating principles had their own inherent magnetism. He wasn't often wrong in that assumption. Certainly, that was true in my case that afternoon, and many, many times afterwards.

He had been appointed as executive director of the Council fairly recently; within the past year. They were working on reconstituting the membership on the Council so that people with disabilities were represented in ways that not only made sense philosophically but also met the requirements of the federal law setting up the councils nationwide, mandating their charters, and including a great deal of progressive language about individual rights and institutional responsibilities. All that was well and good, he said opening up our discussion that afternoon, but you have to work to make it a reality. He was still setting the stage for that work.

In addition to the Council membership, Ethan and the small group of allies he had on board—some people in the Governor's office and the state Division of Developmental Disabilities (DDD); more radical, so called, advocates like him from the disability community; and, key to the efforts, Susan, who had a number of connections in the state's professional advocacy community—were working on fanning interest in getting some of the thousands of people with developmental disabilities out of the state's antiquated institutional system and into their own homes in natural communities throughout, well, anywhere and everywhere.

Bringing people with disabilities out of the shadows and into the light. It was such a simple and foundational message.

I was already thinking about putting in my notice and joining up with this revolution, if they'd have me. As I said earlier, I believe Ethan had already moved on about that.

His passion was infectious. It was infused with his personal experiences and the thousands upon thousands of years people with disabilities had been at the mercy of others. And that was just the recorded years.

It was a history I knew intellectually of course. Hearing him recount it in that voice, slowed down

and deliberate, his hands and arms moving like a conductor's, gave the material new import. He was priming me; putting me on his page. When I thought about it later it was in many ways a masterful interview, as so many of his were, whoever and whatever the subject. For this one, I learned from him while he learned about me.

When he talked about babies left on Spartan rocks to die; people with disabilities sacrificed to pacify primitive gods so they wouldn't make any more of those inferiorities; the supernatural cursed and the tribal fears that they cursed others simply by their being; benign neglect vs. the less-than-benign attentions, like experiments, cures, and lockups—it wasn't just textbook litany. Those people came to life, and death, before me. The "Enlightenment" was maybe only some better. These institutions meant to protect poor vulnerable people from the dangers of the world, when all those same dangers were there inside as well only worse because there was no escaping them. The eugenics movement gave scientific cover to the early outrages of the Nazis and what those led to. After that societies were finally so collectively appalled, they recoiled but they still couldn't quite figure out what to do with people they might not actively want to harm but also did not feel comfortable being around.

Here in New Jersey, the Vineland Developmental Center (Vineland State School at the time) had been at the forefront of the eugenics movement. People with epilepsy and others with disabilities had been split apart from their parents and siblings and experimented on at the Neuro-Psychiatric Hospital, which became the North Princeton Developmental Center, the effects of which spilled over into our lifetimes.

We later highlighted that history in one of the Council's magazines. But I first heard most of the elements of it from Ethan that fateful afternoon. Hearing it then had none of the tediousness often associated with the classroom. It was alive with real people. Their suffering was as real to him as if he had known them all personally. In a certain way he had. Talk about walking the walk. He made it real for me too. He had that gift.

That sorry historical legacy carried over into the present. It was part of Ethan's fiber. It was ever present as he fought to bring his brothers and sisters out of the darkness and into a more civilized light.

The Trenton offices had cleared out, including those just outside the door of the one we were in. The twilight darkened. As it did, he deftly brought the conversation into the present.

There had been some significant progress made federally and in pockets throughout the country. The state's system of services for people with developmental and other disabilities though needed a serious shaking up. Well-meaning or not, it was still a system that was grossly outdated, paternal and patronizing.

His appointment was, in itself, a powerful opening statement. Here he was—a formidable professional with a developmental disability demanding to be reckoned with. Balancing the Council membership was an essential next step. (As an interesting aside here, after his retirement from the state, Ethan continued his tireless work and helped found an advocacy movement by and for people with disabilities called Next Step.)

His vision for elevating the visibility of people with disabilities through a magazine with the same named was inspired. Here were the real-life experiences side by side with news and editorials about the issues they were living with the effects of, both good and bad.

Ethan was an excellent editorialist. His writings further shook up the power brokers of an entrenched system that sorely needed it. In addition to remaking the Council membership and the partnerships that led to the closing of Johnstone Training Center and later, after I came on board, the more massive 550-plus-bed North Princeton Developmental Center, there was the campaign to increase inclusive educational opportunities for students with disabilities; the

creation of a self-advocacy movement; the ongoing service system; the promotion of genuine employment opportunities. Accessibility, health care, recreation, alternative lifestyles, sex (that magazine created just a little backlash).

Later, there was an all-out effort to build a political movement that carried off some pretty impressive statewide conventions, drawing in thousands of advocates and candidates for governor, state and federal legislatures, and one lead-

ing up to the 2000 campaign for president where former Attorney General Janet Reno spoke on behalf of Al Gore.

Significant accomplishments, all born out of Ethan's impressive mind and expansive heart. And underlying it all was that one goal he spoke so passionately of that first evening. Bringing people with disabilities out of the dark; into the light.

It was what he fought for his whole life. Ironically, contrary to his reputation, it

wasn't the fight he loved, it was the persuasion. Not the arguing but the argument. He put up a fight because the reasoned plea had not carried the day and the issue was too important to not fight for. He told me on more than one occasion, it wasn't the battle he was drawn to it was the strategizing; and, given the stakes of most of his campaigns, the success.

It was those sessions that put the mischievous, boy's glimmer into his eyes. That same glimmer I saw on that first afternoon when we talked well past the capitol's closing time. Over the years we had many of those sessions, with each other and with a cast of others. (You all remember). Those are my cherished memories of Ethan. Plotting campaigns, magazines, testimonies, demonstrations, and the like, all in the service of that founding principle of his—that it is wrong for any of us to deny anyone else their equitable place in the human family; their rightful place at the family table. **P&F**

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*Ethan Ellis with
Partners Graduate,
Matthew Payton*

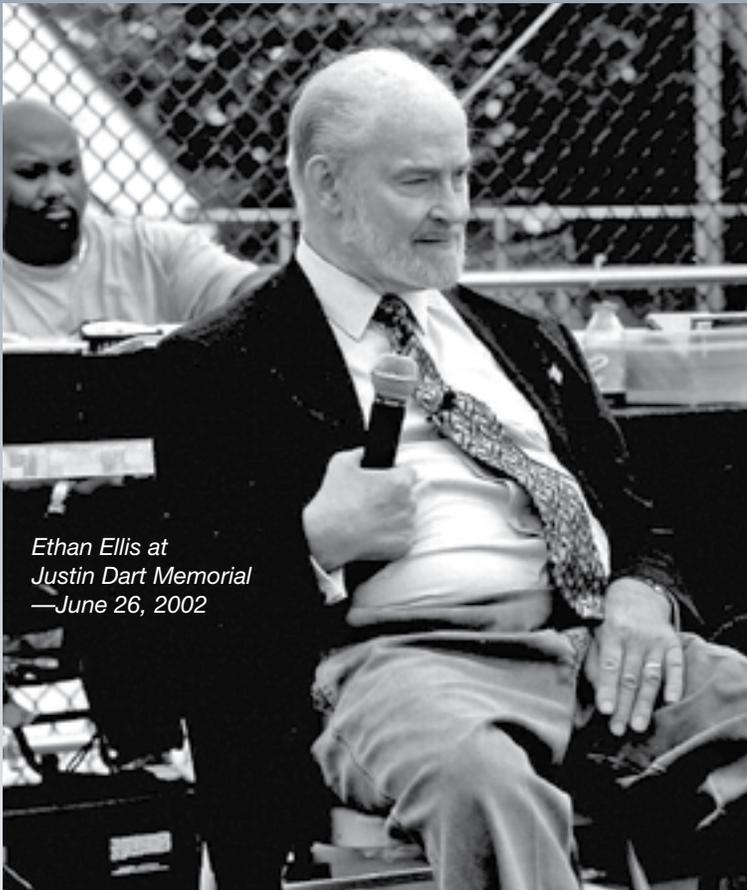


ADA Rally participants cross the bridge at Mill Hill Park in Trenton





*Ethan Ellis attending
the ADA March with
Bob Kafka on July
26, 2005*



*Ethan Ellis at
Justin Dart Memorial
—June 26, 2002*

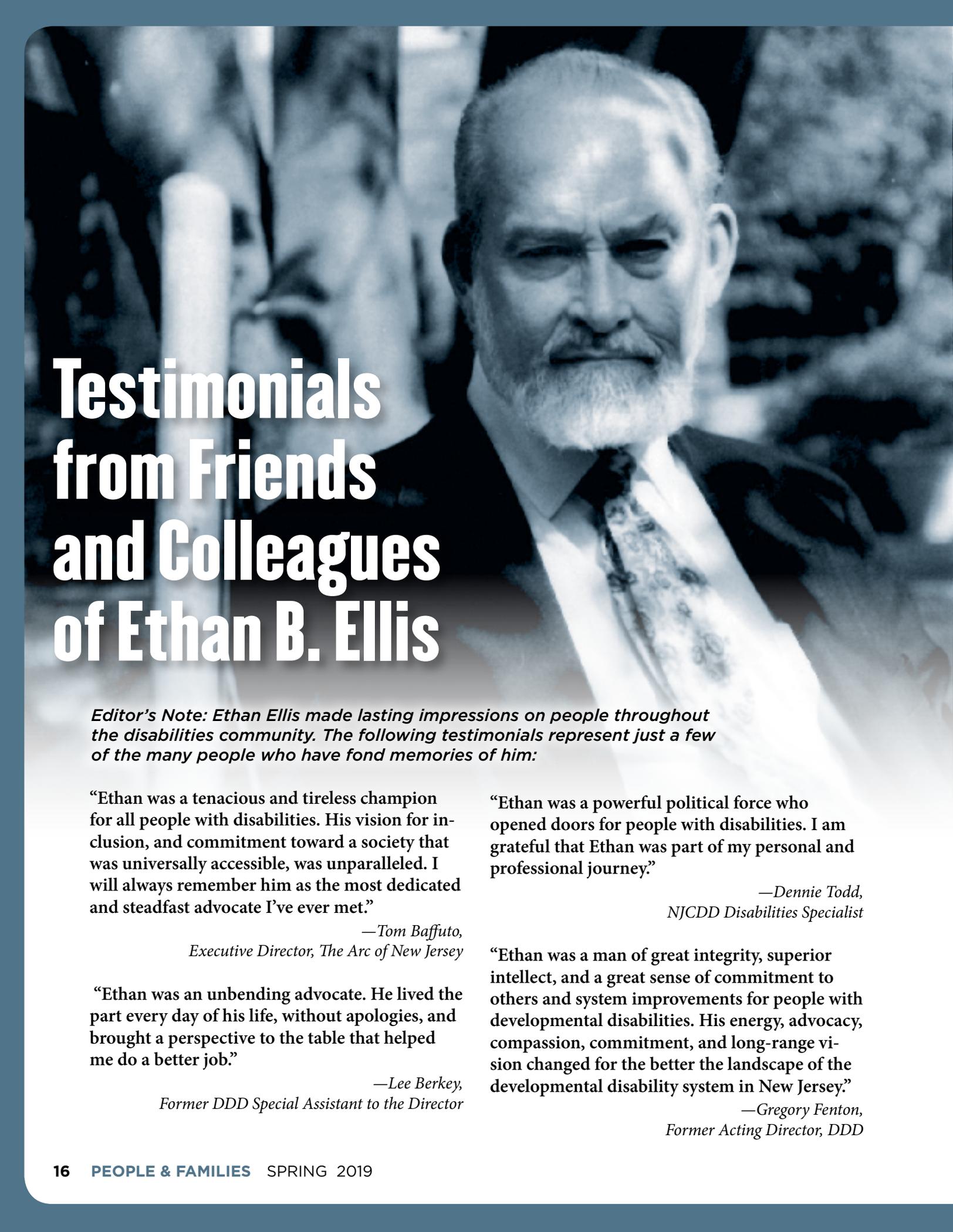




Ethan takes a break from a long meeting



Ethan Ellis with Martin Cole



Testimonials from Friends and Colleagues of Ethan B. Ellis

Editor's Note: Ethan Ellis made lasting impressions on people throughout the disabilities community. The following testimonials represent just a few of the many people who have fond memories of him:

“Ethan was a tenacious and tireless champion for all people with disabilities. His vision for inclusion, and commitment toward a society that was universally accessible, was unparalleled. I will always remember him as the most dedicated and steadfast advocate I’ve ever met.”

—Tom Baffuto,
Executive Director, The Arc of New Jersey

“Ethan was an unbending advocate. He lived the part every day of his life, without apologies, and brought a perspective to the table that helped me do a better job.”

—Lee Berkey,
Former DDD Special Assistant to the Director

“Ethan was a powerful political force who opened doors for people with disabilities. I am grateful that Ethan was part of my personal and professional journey.”

—Dennie Todd,
NJCDD Disabilities Specialist

“Ethan was a man of great integrity, superior intellect, and a great sense of commitment to others and system improvements for people with developmental disabilities. His energy, advocacy, compassion, commitment, and long-range vision changed for the better the landscape of the developmental disability system in New Jersey.”

—Gregory Fenton,
Former Acting Director, DDD

“Advocates like Ethan come along once in a lifetime and I count myself lucky to have worked with him and learned from him. He knew the battle was one of civil rights. He pushed all of us to speak truth to power and do the right thing—not the politically right thing, but the right thing. I considered Ethan a friend, but he was not in this field to make friends—he wanted partners willing to fight for justice, and change, and equality.”

—Brenda Considine,
Considine Communication Strategies

“Ethan always wanted to do the right thing. He was very persistent in his pursuit of improving the lives of people with disabilities. Because of his openness about his disability, parents and individuals could identify with him, and feel confident that he had their best interests at heart.”

—Goldie Ellis,
*Former Assistant Director,
DDD Community Services*

“Ethan was my first director when I came to NJCDD. He was a fierce advocate and a fair boss. He trusted me to do my job and was always willing to help. We lost a very strong voice for the disability community.”

—Gail Furrer,
Former NJCDD Fiscal Manager

“Someone once said, the past is a prologue. Ethan knew the importance of understanding the historical context of issues in order to move forward. He was astute enough to recognize when history repeated itself because others could or did not identify with the historical perspective of key issues.

—Eric M. Joice,
*CEO, Caring America; former CEO,
NJ Epilepsy Foundation*

“I want to make sure that we remember that Ethan was also an artist—a talented photographer. He had an unwavering eye for detail that captured the essence of the events he documented.”

—Deborah M. Spitalnik, Ph.D.,
*Professor of Pediatrics, Executive Director,
The Boggs Center on Developmental Disabilities,
Rutgers Robert Wood Johnson Medical School*

“I feel the sense of loss that NJ’s disability community is experiencing. I am proud to have worked with Ethan and be a witness to the changes he advocated for in NJ. The challenge for us is to take what Ethan has taught us and not back down from the challenges we still face in our society.”

—Luke Koppisch,
ACI Deputy Director

“When I think back on New Jersey’s history of disability rights, I always see Ethan there at key points and milestones leading the way. Sometimes it was a lonely path that Ethan blazed as he forayed ahead of the rest of us, but he forged ahead anyway because it was right and leadership was often needed. Many times on new issues I would ask myself “What will Ethan say; what will his stand be?” We will miss Ethan’s leadership, but we must continue to ask ourselves “What would Ethan do?”

—Norman A. Smith,
*Co-Founder/Associate Executive Director,
Project Freedom Inc.*

“Ethan was my dear friend and mentor. I am proud and honored to have worked with him for close to 15 years. Ethan was tough, with a kind heart. I will forever be grateful for what he taught me and our endless conversations about life. Ethan was an activist up until his last days. Let us honor his memory by continuing the fight against injustice. I will miss you, my friend.”

—Carole Tonks,
ACI Executive Director

“I will always appreciate Ethan’s unwavering determination to remove barriers for people with disabilities. He was a fierce proponent for ensuring that individuals with disabilities achieved successful and fulfilling lives at home and in their communities. I will miss his drive and tenacity.”

—Mercedes Witowsky,
NJCDD Executive Director

P&F

Employment Within the Developmental Disabilities Partner Agencies

By Jonathan Jaffe

Gail Hodges is a rare find, an employee who has already dedicated 25 years of service to the New Jersey Council on Developmental Disabilities as a receptionist.

It is a job the 51-year-old Robbinsville woman enjoys, and she remains truly grateful for the opportunity to secure full-time work. As a person with cerebral palsy, she knows there is not a steady stream of employers who are ready to hire her. Hodges considers herself lucky.

“This is a huge blessing, a gift that was given me,” she said. “Unlike others, I was given a chance.”

Hodges is among the lucky few with developmental disabilities who has secured a career. There are a number of non-profit or government agencies that serve this population and look for candidates who can work in administrative support and other roles. Such employers include, for example, the New Jersey Council on Developmental Disabilities (NJCDD), the Boggs Center and Disability Rights New Jersey (DRNJ).

Hodges was connected to her job at the NJCDD through United Cerebral Palsy, which

also provided her with a job coach as she learned how to answer the phones, greet guests and sort the mail.

“The job coach gave me some pointers, she stayed with me for a little while and she showed me different ways in which to do the job,” Hodges recalled. “I remember losing some of the calls in the beginning, but then I got the hang of it.”

Not only has Hodges been fortunate to have an employer who supports people with developmental disabilities, she has also benefitted from NJ Transit’s Access Link that provides the 11-mile bus ride to Trenton each day, door to door, for her 8:30 a.m. to 4 p.m. shift.

Hodges also lives in her own apartment, sings in her church choir and enjoys going out with her friends, to places like Leonardo’s restaurant in Trenton.

Hodges’ advice for others seeking full-time work?

“You’ve got to go for what you want, if you feel it within your heart,” she said. “Put a resume together, get someone you trust to help you, and just go from there. If it can happen to me, it can happen to you.”



Gail Hodges works at the NJCDD Trenton office.

Dedication has paid off for Jeremy Einbinder, a blogger who writes from his home in Westfield. The 26-year-old writer, a graduate of Rowan University, also has cerebral palsy. He said the disability makes it difficult to interview people, because his speech can be slurred. But he is proud of his crisp, professional writing that is not hampered.

Einbinder has developed a nice stable of clients. He blogs for the NJCDD each month, while also doing freelance work for a public relations firm, copy editing for an IT company and writing a sports philanthropy blog.

But he is not satisfied. Einbinder is eager to work in a traditional office, rather than his home.

“I’d like a place to go on a regular basis, but it is a challenge to find employers with offices that are

accessible,” Einbinder said. “Also, I can’t do manual labor, which makes it harder for me to find work. So, I get my voice out through the Internet.

“When you are on your laptop writing, people don’t see you using a wheelchair, or hear how you sound, or see your sporadic body movements, or tics, or that you may have trouble breathing,” he added. “They just read your words and they take you seriously as a writer, and as a disability advocate.”

Hiring people with developmental disabilities is a natural fit for the Boggs Center, based in Piscataway. The ongoing goal is to develop the type of workforce that aligns with the diversity of the state as far as race, ethnicity and level of ability, explained Colleen McLaughlin, the center’s associate director.



Jeremy Einbinder writes a blog for NJCDD at his home in Westfield NJ.

“We are tasked with education, research and service,” she said. “We do a lot of professional training and we have a team focused on employment, with successful transition from high school to adult life in a meaningful way.”

The Boggs Center provides training and technical assistance on the benefits of employment and securing work for people with a wide variety of disabilities, McLaughlin said.

One beneficiary at the Boggs Center is Kim Tomlin, who has worked there as a receptionist for about a decade. Similar to Hodges, Tomlin greets guests and answers the phone, as well as types up the schedule for the coming months.

“I really like working at the Boggs Center,” she said. “They are my work family. Everybody is nice and kind.”

Tomlin, who has learning disabilities, has had other jobs in the past, such as working in a library to shelve books and to serve as a teacher’s assistant at a YMCA in Princeton. “Work has never been new to me,” she said, noting she likes the independence that a job creates. She is also pleased to have the self-sufficiency of taking a bus to work from her home in Franklin Township.

Tomlin is also fortunate to have a job coach through the state Division of Vocational Rehabilitation (DVR), which is part of the state Department of Labor & Workforce Development.

For other people with disabilities to succeed in the workplace, Tomlin says that supports, such as job coaching, are critical. They also need to keep an eye out for jobs of interest and work with the DVR to help identify opportunities.

“DVR has many programs and resources,” she said. “The division also provides you with training and the ability to meet with your job coach.”

Tomlin said her job at the Boggs Center has been a perfect fit, as the organization is dedicated to providing training for people with developmental disabilities, as well as self-advocacy.

“Employment of people with disabilities is an important job that we all have,” McLaughlin added. “We need to work to help people have truly integrated lives in the community and

recognize that having a job is possible for anyone.”

Gwen Orlowski, who began her work as executive director of DRNJ on January 3, said the statewide self-advocacy organization employs people with disabilities in various roles, from basic administrative support to higher-level positions, such as policy and legal experts.

“We have people with disabilities in all kinds of jobs, which are valuable and essential, among our 36 staff members” she said. “I hope when people think about applying here, they know we employ a workforce representing people with disabilities across all job titles. We have no specific category of jobs available just for people with disabilities. The opportunities are across the spectrum.”

Having a job is all about self-sufficiency for Barb Coppens, who does general office work for the DRNJ in Trenton. Each morning, the Cherry Hill resident rides her bike to the Palmyra station of the New Jersey Transit light rail. For just 75 cents, the train takes her to the Trenton Transit Center in just 45 minutes. From there, she pedals her bicycle to the office on South Broad Street.

Coppens has an important job, in which she drops off all the DRNJ mail at the Richard J. Hughes Justice Complex on Market Street in Trenton. She also hand delivers information to her organization’s staff of attorneys.

“I am also filing cases that are closed, assembling booklets for outreach and answering the phones,” said Coppens, who has intellectual and developmental disabilities. Coppens is proud to note she landed the job on her own, beginning July 18, 2005, as the DRNJ leadership was already aware of her advocacy work.

Coppens, a proud self-advocate, said she has a responsibility to others with disabilities who are seeking work: To keep an eye out for any and all opportunities.

“When we hear that someone is hiring, we need to let others in the community know about it,” she said. “We need to give others advice, to help them put a resume together and prepare them for the job. People with disabilities are like anyone else; they want to work and need to work. They just need a little help. That’s all.” **P&F**

Alliance Center for Independence

Opening Doors for Students with Disabilities

By Maryann B. Hunsberger

When Spencer Heisler met Rachel Gabrilowitz at the Alliance Center for Independence (ACI), an Edison-based center for independent living, he was working at the wrong job.

“I worked at Wendy’s and I wasn’t enjoying it at all. I was a cashier. It was stressful. I was constantly standing and my back hurt,” said Heisler. When returning a book to the library near his Edison home, Heisler noticed an ad for a library page, a position that involved putting away and organizing books. He thought the slower-paced job would be a good fit, but he didn’t know how to get the job.

Gabrilowitz, an employment coordinator, helped Heisler create and tailor a resume for the position. She assessed his strengths and weaknesses and realized that he needed to improve his interview skills. She researched questions that he might have to answer when interviewing for a library position. Then, they went over the questions together, prepared answers and did mock interviews. “She taught me how to do better and how to sound more professional.” Heisler aced the interview and got the job.

Heisler, 18, came to ACI through a referral from the New Jersey Division of Vocational Rehabilitation Services (DVRS). This process, called Pre-Employment Transition Services (Pre-ETS) is for eligible students with disabilities between the ages of 14 to 21, including home-schooled students.

ACI also has a grant from DVRS called PETS, which also stands for pre-employment transition services. The difference is that Pre-ETS is a fee-for-service program, and PETS is a grant program where students work in groups. The eligibility for both programs is the same—students must have an IEP or 504 Plan and a referral from DVRS.

These programs were started because of a new law, the Workforce Innovation and Opportunity Act (WIOA) of 2014, which amends the Rehabilitation Act of 1973. This law mandates that DVRS work more closely with transitioning students with disabilities at age 14.

Luke Koppisch, deputy director of ACI, explained that although transition services existed before WIOA, the new law assures that students are prepared to work when they graduate. “We’ve

always done transition, where the schools would refer us and DVRS after graduation. Now we work with them while they are still students. We no longer have to wait until the students graduate to prepare them.”

Gabrilowitz is excited that WIOA provides transition opportunities at an earlier age. “I think it will help prevent students from leaving high school with no career interests or independent living skills. We see people come to us in their early 30s who never had a job. So, it’s absolutely great to start getting students to think about transitioning at 14. It’s good to see students learning the skills to get a job and to know which resources to use to get a job in the future.”

Through the PETS grant, Gabrilowitz works with groups of students in schools in Somerset, Union and Middlesex counties. The district child study team identifies up to eight students who will participate in each group. She works with the same students once a week, focusing on the five WIOA components. Those include job exploration counseling, a work-based learning experience, instruction in self-advocacy, workplace readiness and counseling and guidance for post-secondary options.

She said, “We do mock interviews and we learn interview etiquette. Since all students are different and have different goals, it’s less about telling them what to say and more about helping them figure out what feels most natural to say in interviews. We talk about how to maintain employment by managing anger and interacting appropriately with coworkers and supervisors. We focus on independent living skills, including budgeting, understanding a paycheck, taking public transportation, learning how to manage money and using money tools such as checking and savings accounts.”

What makes the grant program unique is that at the end of the program, any students who are ready and want to demonstrate the job skills they learned can have a paid internship opportunity. “It provides work-based learning in a real life setting. Since this is the first year the grant program is being implemented, we are currently finding the companies to do this. A lot of companies are open to the idea. There isn’t a cost to them, as the



Spencer Heisler working at Claire Barton Library in Edison, NJ

pay comes from our grant. This makes it more attractive to the employers.”

The employer must provide the training, so the students must be capable of working independently. “The students’ teachers decide if a student is capable of participating in the work-based learning part. There are students who might go through the program, but not be paired with an internship. We don’t require it. It’s optional for students.”

ACI also provides higher education counseling. “If a student wants to go to a vocational school or a college, we can help them figure out their options. We use tools to help students find their strengths and career interests and we look to see which schools have the best options to reach their career goals. We go over the different programs available at each school and see what’s required to apply. We might show them a sample college application or find dates for college tours.

I might guide them in how to write their college admissions essay. It's good to have that extra support. I'm in the midst of bringing in college disability services officials to speak to the students."

Heisler was one of the students who Gabrilowitz helped with college preparation. They practiced for college interviews. She also helped him understand different parts of the college application process. This supplemented what he learned about the college application process during his senior year at Edison High School.

Heisler said, "Rachel provided services to help me get through senior year and prepare for college. She worked with me one-on-one, teaching me how to create a college resume and make it official looking. When I had to fill out my college application, she made the whole process a lot less cumbersome. She would always have different documents for every situation I'd come in to discuss."

As someone with Asperger syndrome, communication is difficult for Heisler. "ACI helped me with talking to people and interview skills. I used to psych myself out and get all nervous. I'd tell myself I wouldn't be able to do it and it would be

hard. Rachel helped me to calm myself down and not be so worried beforehand. She helped me prepare myself in my head for having a conversation with someone. I wouldn't be doing as well with the interview for this article if I hadn't worked with Rachel."

Heisler was accepted by Rider University where he will major in graphic design. As is typical of people on the spectrum, Heisler needs improved organizational skills. "It's the college workload that concerns me. Rachel helped me with how to do scheduling, how to break down what I have to do into different parts, how to plan and prepare. I never used the calendar in my phone until Rachel got me to write dates in my phone to remember things. Also, we worked on timing and how to not procrastinate, so I wouldn't wait until the last minute to do things. She taught me to make a schedule of everything I have to do. It was very helpful."

Koppisch said, "Our job is to open the doors for them, guide them through the process, and give them skills." With these new programs, ACI has a better opportunity to do exactly that. **P&F**



Common Ground Online
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New Jersey's Special Education System

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FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

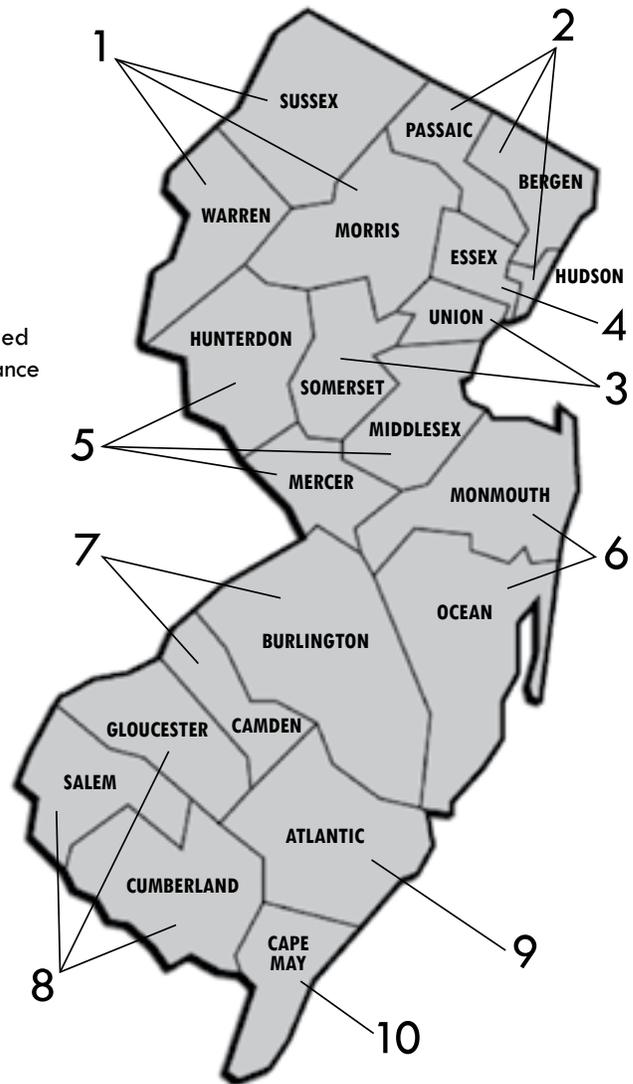
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

A number of regional councils were established in New Jersey by the *Family Support Act* of 1993 (see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and other forms of assistance that promote self determination, independence, productivity, and integration and inclusion in all aspects of community life.

The councils work in partnership with the state's Division of Developmental Disabilities and Children's System of Care to advise on policy decisions that affect people with developmental disabilities. Councils sponsor events where individuals and their families can learn about the services available in the area, as well as host public forums to solicit feedback from the community. In addition, councils regularly distribute literature with important information for people with developmental disabilities and their families.

Family members of people with developmental disabilities can volunteer to serve on their regional planning council. Council members assist and advise the Division of Developmental Disabilities and Children's System of Care as to how resources can best meet the needs of families and individuals living in their region.

Councils meet regularly—usually once a month; each Council may have up to 11 members. Council members are volunteers but will be reimbursed for reasonable transportation, child care, and other costs related to serving on the council.



For more information, Call the Statewide Family Support Coordinator Kyoko Coco at 609-341-3112 or email her at kyoko.coco@njcdd.org

Or visit our website at www.njcdd.org and follow the link to Family Support & Facebook page at www.facebook.com/NJFSPC.

THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with developmental disabilities.

Visit the NJ Council on Developmental Disabilities' web site at: www.njcdd.org,
click on the link for Family Support, and the number corresponding to the
Regional Family Support Planning Council in your area.

1 SUSSEX, WARREN, MORRIS

RFSPC#1
e-mail: rfspc1@gmail.com
Chair: Margaret Hefferle

Meets the third Tuesday of each month
Wegmans Market Cafe
34 Sylvan Way
Hanover, NJ 07054
7:00 p.m.— 8:30 p.m.

2 BERGEN, HUDSON, PASSAIC

RFSPC#2
PO Box 443
Jersey City, NJ 07302
e-mail: RFSPC2@gmail.com
Co-Chairs: Dorothy Blakeslee, Fel Lim

Meets the third Monday of each month
Secaucus Public Library
1379 Paterson Plank Rd.
Secaucus, NJ 07094
6:30 p.m.— 8:30 p.m.

3 SOMERSET, UNION

RFSPC#3
e-mail: rfspc3@gmail.com
Chair: John Brewer

Meets the third Tuesday of each month
Arc of Somerset County
141 S. Main St.
Manville, NJ 08835
7:00 p.m.— 9:00 p.m.

4 ESSEX

RFSPC#4
e-mail: rfspc4@yahoo.com
Chair: Yolanda Smith
Co-Chair: Phyllis McNair
Vice-Chair: Eileen Hurley

Meets the first Wednesday of each month
Bloomfield Civic Center Music Room
84 North Broad St.
Bloomfield, NJ 07003
7:00 p.m.— 8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5
e-mail: rfspc5nj@gmail.com
Chair: Paul Blaustein

Meets second Saturday of each month
South Brunswick Library, 110 Kingston Ln.
Monmouth Junction, NJ 08852
10:00 a.m.— 12:00 noon

6 MONMOUTH, OCEAN

RFSPC #6
PO Box 76
Lakewood, NJ 08701
e-mail: rfspc6-chair@excite.com
Chair: Mike Brill

Meets the second Thursday of each month
Brick Municipal Bldg.
Council Rooms A&B
401 Chambersbridge Road
Brick Twp., NJ 08723
7:30 p.m.— 9:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
e-mail: rfspc7@gmail.com
Co-Chairs: Laura Kelly
Lisa Weissbach-Effrat

Meets the second Thursday of the month
Wegmans (Cherry Hill, NJ) 2nd floor cafe
2100 RT-70 W
Cherry Hill, NJ 08002
Even months: 7:00 p.m.— 8:30 p.m.
Odd months: 12:00p.m.-1:30p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
e-mail: RFSPC8@gmail.com
Chair: Sandra Backensto

Meeting times and dates TBD

9 ATLANTIC

RFSPC #9
e-mail: RFSPC9@yahoo.com
Chair: Mary Ann Philippi

Meeting times and dates TBD
Arc of Atlantic County
6550 Delilah Rd., Suite 101
Egg Harbor Twp., NJ 08234

10 CAPE MAY

RFSPC #10
PO Box 199
South Dennis, NJ 08245
e-mail: RFSPC10@yahoo.com
Chair: Anne Borger

Meets the third Thursday of the month
except January, April, July, August and
December
Cape May Special Services School
148 Crest Haven Dr.
Cape May Court House, NJ 08223
6:30 p.m.— 8:00 p.m.

The Art of Business: The Business of Art

By Brenda Considine

Kristen Zachares has long been an artist and a creator. Now, the 32-year old New Jersey native is also an entrepreneur, net-worker, and business owner.

Kristen owns The Eclectic Chic Boutique in trendy downtown Montclair, New Jersey. The busy storefront is a collaborative with more than 30 artists that she created to connect creative entrepreneurs to more customers. It is also a maker's space and "incubator" for young artists and crafters.

For more than a decade Kristen had been making jewelry, paintings, illustrations, and textiles. As she toured craft shows selling and showcasing her work, she was also testing the market and networking with other artists.

"I found there are two types of artists: those who loved making art, but who did not like to sell it, and those who loved what they were doing, but did not have time to do it because of demands of full-time work or family," said Kristen.

She networked with them and offered to help by selling their items at community art shows through a mobile consignment business. At one point, she even sold items from her living room.

"People kept asking me, 'When are you going to open your store?'" said Kristen. That was the turning point.

Through a longtime connection with Arts Unbound, an organization dedicated to the

artistic achievement of individuals living with disabilities, Kristen was introduced to Rising Tide Capital. The non-profit, based in Jersey City, helps individuals create their own businesses and strengthen local communities. Its mission is to equip talented but under-resourced individuals with the tools to create businesses that change the trajectory of their lives. Kristen took their 12-week program, which opened up a new world for her. It also exposed her among the nearly 2,400 entrepreneurs who graduate from their Community Business Academy.

Kristen learned hands-on, practical business skills and applications: how to manage cash flow, work with other businesses, and develop a business plan.

"It opened my eyes, not just to my selling position, but how to create more cash flow. I decided then that when I opened my store I would make it an artisan membership," she said.

After the course, Kristen knew she had the skills to launch her business, but she still lacked the money.

"Banks would not even consider giving me a loan," she said. "I knew I needed to get very creative."

Through Rising Tide, Kristen learned about no interest crowd-sourced loans, which got her started. But she was still short of cash, so she turned to her support coordinator at Neighbours, Inc.



Kristen Zachares, owner of Eclectic Chic Boutique stands in front of the display, Mellow Works, which makes modern stationary and home goods by Divya Guruju.

The statewide non-profit provides the support coordination services Kristen needed to make her endeavor a success. According to Annette Smith, a support coordinator and community navigator at Neighbours, the organization helped Kristen through a unique savings plan.

“Kristen took advantage of our Individual Development Account (IDA) for several years, allowing her to save money for a deposit on the store and for signs and fixtures,” Smith said. “Our IDA is supported through fundraising and provides a three-to-one match—for every dollar the individual puts in, we match three. The matching funds are donated by Neighbours International and funds raised by the Jimmy Scott Fund,” she said.

According to Smith, the funds are not paid to the individual, and there are specific guidelines as to what funds can be used for: starting a business,

Rising Tide Capital

Rising Tide Capital provides business management, planning, and support services to entrepreneurs looking to start or grow a business through three discrete programs:

1. The Community Business Academy, providing hands-on business management training to start or grow a business;
2. Business Acceleration Services, to support and accelerate business goals;
3. Credit to Capital, to help entrepreneurs get working capital with a one-to-one business coach.

A new Rising Tide business opens every seven days, and within two years of graduation, entrepreneurs experience an average 112 percent increase in business revenue and 58 percent increase in household income. The incomes they generate return \$3.80 for every dollar invested.

continuing education, medical equipment that is not funded under insurance, a down payment on a home, or work to make a home accessible.

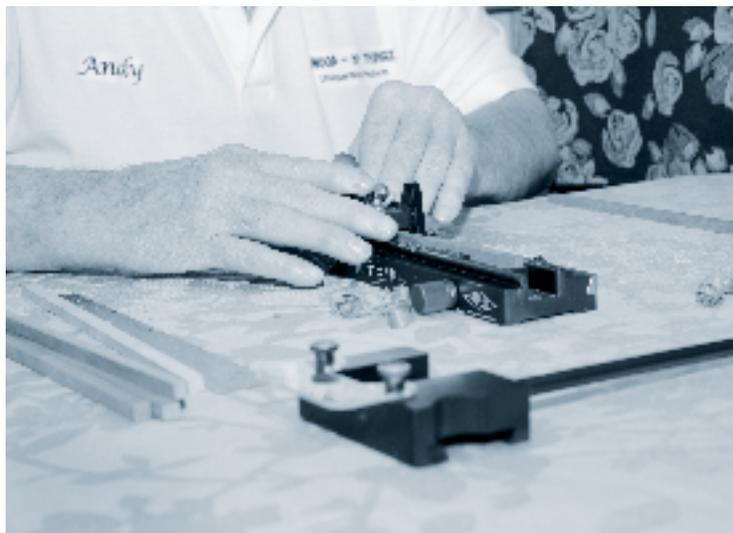
“The IDA account was an incredible opportunity. It allowed me to put money away without being penalized for it. They matched the funds, so the savings grew quickly. And it was not a loan, so I did not have to pay anything back,” Kristen said.

Armed with the skills and the funds she needed, Kristen opened The Eclectic Chic Boutique in February 2017. For her customers, she offers an eclectic collection of handmade items, from soaps and candles, to woodworked crafts, hand-knit items, artisan jewelry, and homemade jellies and jams. She also offers classes and programs, including a new summer camp scheduled to open this summer. She even offers a child-friendly/pet-friendly shopping experience and personalized shopping support for those with special needs.

For the artists who join the collective, she offers more than just a place to sell their work—she offers space for meetings and events, a place to showcase and take pictures of work, and a space to make art.

The cooperative business model gives Kristen the cash flow and the help she needs to run the business. Promotion and marketing is a team effort, and doesn't rely solely on the individual

Andy Cole uses a special machine to make chopsticks out of scrap wood.



Individual Development Account

Q: *What is an IDA?*

A: IDAs enable low-income and low-wealth individuals to save for specified goals within defined time frames. The typical savings goals of those with IDA accounts are homeownership, small business ownership, and post-secondary education.

Q: *How does an IDA work?*

A: IDA programs are offered as partnerships between sponsoring organizations (often nonprofits or state and local government agencies) and national banks and federal savings associations (collectively, banks) and other financial institutions. They have been in existence since 1990, and are similar to the matched savings arrangements in 401(k) plans. An individual puts their own money in, and partners match it.

Q: *How do IDA partnerships work?*

A: IDA partnerships usually include non-profit or government agency sponsors and banks. They may operate as single programs or regional or statewide collaboratives. The sponsors are responsible for fundraising and program administration, including participant solicitation, training and technical assistance, and programmatic casework. The banks are responsible for holding the sponsor's and participant's accounts, and complying with program and regulatory requirements. The banks may also support the programs through operating grants to the sponsoring organizations and/or contributions to the program match fund accounts.

artists. The member artists help by working in the shop or using social media to spread the word.

That kind of help cuts both ways, according to Mandy Lezcano, Kristen's support broker. “Kristen has a mission to give back through her art program. She is always open to finding ways to help others,” she said.

Through Neighbors, Inc., Kristen has a direct support staff person who helps her at the shop 15 hours a week. Prior to that, she had a job coach to help her start the business.

“Kristen also has a lot of mentors in the arts community, who provide natural supports to assist her,” added Lezcano.

For others who dream of starting a business, a creative approach to funding is a must. According to Smith, one of the major barriers for would-be entrepreneurs is simply not understanding how to save money in a way that does not jeopardize funding for support and services. The IDA is an important piece of the puzzle.

“Most financial assistance programs offered to individuals with disabilities have a limit on how much you can save before they jeopardize their funding. For example, if they were to open a typical savings account, if the account reaches any amount over \$2000 in a month the individual would automatically become ineligible for any assistance,” she explained.

Kristen advises others who want to start a business to keep an open mind and look for opportunity wherever it comes.

“You do not need to rely on traditional methods, but you do need to be surrounded by people who believe in you,” she said. “Even family members—as much as they love you—still see your disabilities, not your abilities.”

“There were times when people did not believe in her dream, but she kept right on going,” said Smith.

Kristen also urges others not to be afraid to ask for help with things that are not your strengths.

“I need help with computers and finances, and they are an essential part of the business. But needing help did not prevent me from opening the store,” she said.

“My disability is autism-related, so initially, I felt it inhibited my social and communication skills. What I have learned is the best way for me to connect is through business and shared interests. Now, a lot of my friends are business owners and other women who understand what it means to be in that world. It took a while to teach myself to read the cues and body language,” she concluded.

Lezcano sees the business as a tremendous growth opportunity for Kristen. “Since I have



Kristen Zachares and her partner Miles Cohn at Eclectic Chic Boutique. They are standing in front of J Lexi, owned by Celeste M. Munford of Orange NJ. She makes products for skin, hair and beauty.

known her, her confidence and her social skills have improved and now she is able to put herself out there. She has worked really hard to reach her dreams and goals.”

Her next goal is big: According to Lezcano, Kristen wants to make enough money in her business and get the skills she needs so that she no longer needs to be part of the DDD system.

“People do not need to know that you have a disability, but you don’t have to try to hide it either. You being your own quirky self is OK,” said Kristen.

“Once you are honest with yourself, and if you just BE yourself, others will accept you and you will succeed.” **P&F**

Resources

Arts Unbound

(973) 675-2787

<https://www.artsunbound.org/>

Rising Tide Capital

(201) 432-4316

<https://www.risingtidecapital.org/>



Changing Lives through Vocational Training

By Maryann B. Hunsberger

Andrew Monti, the receptionist at The Arc Mercer's (Arc Mercer) occupational training center, is a busy man. Besides doing typical front desk work, he helps load and unload attendees from buses, vans and cars as they come and go to and from their daily work site.

Some might find it hard to believe that he once attended the occupational training center. "Five years ago, he sat at a day program at a table and wasn't fully engaged," said Steve Cook, who serves as the executive director.

Monti changed his life by learning skills through Arc Mercer's vocational program. Their office skills training program is modeled after a county college administrative assistant certificate program. Participants learn front desk skills, mail handling, message taking, shredding, data entry and scanning. Each element is adapted to fit the needs of the individuals served. "We have placed some clients who do fantastic work in this field," said Cook.

Every program is designed around a curriculum that will lead them to a recognized certification at the end. "Years went into developing the training programs. We base the curriculums on actual credential requirements." In all training programs, Arc Mercer tries to negotiate with the certification entity for accommodations, such as skill demonstration instead of written testing. If this isn't possible, the student receives an Arc Mercer certificate of accomplishment that many local businesses recognize.

Students with disabilities can get a jump on Arc Mercer's vocational training while still in high school. During the school year, groups of Mercer County students participate in Arc Mercer's daily vocational programs. After learning their daily

academics at school, the students are brought to the vocational location by school staff.

For a fee, students can also attend a six-week summer vocational camp. "The first summer, they are exposed to one of six fields of study each week. In the second year, they pick a field and immerse themselves in it. During the third summer, we get them ready to enter a full training program after graduation," said Cook. If students choose, they can do both the daily vocational training and the summer camp.

Once students age out of school, they can attend the adult vocational program. Cook said that some individuals know what they want to do, while others need help figuring it out. "When they have no idea what they want to do, we let them do some exploring. Then we train them, get them supervised work experience with a job coach, help them find a job and place them." If consumers can't find a job in the community, this training allows them to work for Arc Mercer in one of their social enterprises. "We have a full catering operation, which makes thousands of meals each year. We also have a cleaning operation, which has built a workforce that cleans more than 2.6 million square feet of office space every day."

More than 300 people with developmental disabilities receive a paycheck thanks to Arc Mercer's vocational program. Arc Mercer offers supported employment and long-term follow-along services for all training programs. Besides office skills training, they also have training programs for auto repair and detailing, landscaping and maintenance, document shredding, food service, fulfillment, hospitality and janitorial. A pet care program is also in the works.

Auto Repair and Detailing:

At their auto repair and detailing training program, participants learn minor auto repairs, such as oil changes. They may achieve a certificate of completion in the area of auto maintenance and repair or auto detailing and light maintenance. “The car detailing is great. It looks brand new when they are done with it. We trained an auto detailer to be a job coach for this program, since all our coaches must demonstrate proficiency in both doing and teaching the work,” said Cook.

Landscaping and Maintenance:

The Landscape Industry Certified (LIC) distinction is given by the National Association of Landscape Professionals (NALP). But, sometimes individuals might just want to learn about landscaping for their own enjoyment. “Our landscaping horticulture program isn’t always about getting a job, but sometimes about learning to plant a garden. Our goal is to assist in providing opportunities for realizing one’s potential.”

Document Shredding:

Arc Mercer follows guidelines outlined by the National Association for Information Destruction (NAID) for the destruction of materials. “Local

Dan Artman (pictured right), works in the Arc Mercer transportation department with his supervisor Mike Courtney.



Photo courtesy of the Arc Mercer



Photo courtesy of the Arc Mercer

Tanya Williams, works in the clerical department with her job coach Erris Ivory.

businesses trust us because we do ongoing work with them. For instance, we have a relationship with a local franchise of Shred-It. We have a group of consumers who do training there with job coaches. Shred-It sometimes hires these trainees.”

Food Service:

Students who complete the food service program are certified to work in food-related businesses, such as restaurants, food markets and cafeterias. The program is based on ServSafe, the food service industry standard. Training is complete when students can successfully run a shift at Arc Mercer’s café—from food preparation, to food server, to cashier. Arc Mercer has established a network of food-related businesses that are looking for qualified food-service employees, such as Rider University. Program graduates can find work in one of these companies. Or, they can choose to work for Arc Mercer in their café or in their catering operation.

Fulfillment:

This program is for individuals who are interested in packing and shipping. Students learn things like assembling boxes and dividers, shrink wrapping a pallet, maintaining a facility and understanding shipping and receiving information.

Hospitality:

The hospitality program is a cross between janitorial and food service. People work in jobs such as catering or hotel cleaning. They can work at Arc Mercer's social enterprises or in the community.

Janitorial:

The janitorial program teaches students to meet ISSA CITS (International Sanitary Supply Association—Cleaning Industry Training Standards) certification. "We employ some individuals in our janitorial business enterprise, said Cook, "Others get jobs for commercial cleaning services. Our clients don't just get jobs as janitors, but as site supervisors who manage other janitors with and without disabilities."

Pet Care:

A pet care program, which is in development, will mirror a community college veterinary assistant program. People with special needs will learn valuable skills, and get volunteer experience at shelters that can lead to paying work. Some

people might want to use this training to learn how to take care of a pet or to learn to create foster homes for pets in their supervised apartments or group homes.

The Arc Mercer also has an occupational training program for people whose employability is limited. "We have about 141 placements there. Some work for us for many years. Others can eventually get jobs in the community."

Cook cautions against thinking that anything is too hard for anyone. "We have so many career tracks because what one person thinks is hard, someone else might be tremendous at it. We provided transportation training to a person we support, James Marino, and hired him as a driver for our transportation department. We provided training for, Dan Artman, who had an interest in computers. He is now doing great computer technology work in our transportation department. We build businesses, create job opportunities while employing and promoting people to leadership roles. There are real limitations in the world, but we approach things as though they are just perceived limitations." **P&F**

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participate

A UNIQUE APPROACH TO READYING STUDENTS FOR WORK

By Maryann B. Hunsberger

As a student at Film Academy 360, Alexa Girard of Califon learned creative and technical skills in filmmaking, video editing, production and publishing. She has also taken part in in-house commercial production, work and education preparation and community volunteer and internship placements. She also learned the basics of how to get a job.

“My teacher, Mr. Di Ianni, taught me that I must look and dress presentably and act and dress grown up in a business or work setting,” said Girard. “He also taught me that in order to be a professional, I must listen and be attentive at all times. It’s unprofessional to wear casual clothes or show your frustration in the workplace.”

Those words of wisdom have paid off for Girard. Thanks to the many skills she learned at Film Academy 360, she secured a nine-month internship at Pfizer in New York City (NYC). Along with Dominic Magi of Oakland, she works 20 hours a week for \$16 an hour in the Business Technology Department. The students commute independently, taking buses to the Port Authority bus terminal in NYC and then a crosstown bus to Pfizer. Their family members taught them how to do the commute. Film Academy 360



Alexa Girard at the entrance of the Pfizer headquarters building where she works in midtown Manhattan



Film Academy 360's Dominic Magi interns with Pfizer.

plans to provide transportation training as soon as the next internships start.

David Di Ianni, project director of Film Academy 360 said, "It's great to see the students achieving these kinds of things. They travel, navigate their work day independently in a corporate office, check in with security, log their hours, ask for their daily assignments, go to lunch and have typical workplace conversations with their coworkers. A supervisor told me that they have become 100 percent part of the team."

Girard, age 20, agreed, saying, "I am included as part of a team and get along great with my coworkers. The people there are so nice, friendly and easygoing. I'm really happy there and I like my job."

Di Ianni explained their unique approach to readying students for internships. "I approach the employer, ask what position they need to fill, and ask them to help me develop a curriculum to train the students to be more successful. We call this reverse design. We start with the job and build the curriculum to teach those skills."

The New Jersey School Boards Association recently presented Film Academy 360 with an

Innovation in Special Education Award for its original way of engaging special needs students and preparing them for social and vocational success.

Film Academy 360 offers hands-on education in a team-oriented environment for students who are interested in filmmaking. Film Academy 360 is a program of Spectrum 360, a North Jersey-based nonprofit organization serving 350 children, adolescents and adults with autism and related disabilities. They serve people over 21 in their Independence 360 program. They serve students, ages 3 to 21, at two schools. Besides offering film and culinary classes at their school, they offer Film Academy 360 and Culinary Academy 360 after school, on weekends and in the summer months. These two programs are open to students attending other schools and to adults on the spectrum.

Magi, 32, is one of the adult students who attended on summer weekends. He now has an internship at Pfizer. "There were some adjustments I had to make, as this is my first job in the corporate world. I had to get used to waking up very early. Commuting had its own difficulties, as

the first bus I used was in a different county. My parents found a bus that was closer to my house and I have been using it.”

He has now adjusted to life in the working world. “This is a new experience, as I’m a part of a team. When I ran into problems at work, I had help from my coworkers who were very understanding. Overall, there were some difficulties at the start, but with the help of my family and coworkers I have learned how to work in a corporate workplace.”

Girard also has adapted to the changes in her life, including learning things at her internship that she hadn’t learned at school. “The training I got at school helped me feel confident and excited about taking this internship. I learned a lot of skills at Film Academy 360, such as how to edit videos. At Pfizer, I do a lot of computer work editing videos of their daily business meetings. I use a program called WebEx for this. It’s new to me, as I used a different program at school. I’m a pretty fast learner, though. I also use Excel for working on documents, such as attendee reports for meetings. I learned how to do attendance reports and daily video schedules. I then give the reports to my supervisors. This really helps me to learn. The supervisors have taught me all of this.”

Di Ianni said he credits the supervisors and team for helping the students become part of their work mission. “The team’s ability to make the students feel welcome is the biggest factor in their success. The team also gains a lot from their willingness to include people with autism. This diversity gives a broader meaning to their work, giving them a new work mission that is really important.”

Film Academy 360 is expanding their internship placements by negotiating with three other multinational corporations for the same opportunities. Di Ianni said, “We are riding the wave of

businesses in America reaching out to organizations like ours for diverse candidates. This trend toward hiring diverse individuals enables us to expand our mission. I tell hiring managers it will take commitment, time and effort, but it will include people with autism who will do a job very well and will continue to do it.”

Film Academy 360 is now working on a partnership with mandy.com, a job board. NYC TV and film producers use this site to staff their

productions. “It’s primarily for freelance work. The staff there is supporting our students through training, free subscriptions to the site, and advocating with NYC producers to hire their students for disability inclusion.”

Di Ianni is proud of the accomplishments of both Film Academy 360 and of his students. “Dominic has been able to socialize and find many things in common with his new coworkers at Pfizer. He is able to complete his assigned tasks and independently manage all aspects of his work day. Dominic is very proud of his new role.

“Alexa was very concerned about her ability to take public transit independently and then do the tasks assigned to her. She is now expert at her commute from New Jersey to Pfizer headquarters in NYC and has been able to complete the tasks assigned to her by her supervisors and coworkers. Alexa now believes that she can do anything she decides to set her mind to.”

Girard said, “I have autism, a disorder that makes me lack social skills. Working at Pfizer has helped me improve them. I’m less shy and more outgoing now. I want to thank my supervisors and coworkers for helping me come out of my shell. My confidence has improved all around from the internship. I’m really proud of myself for being a big help to the company and my superiors. It’s a great opportunity. I’ll never regret it and I’ll remember it for the rest of my life.” **P&F**

“My confidence has improved all around from the internship. I’m really proud of myself for being a big help to the company and my superiors. It’s a great opportunity. I’ll never regret it and I’ll remember it for the rest of my life.”

—Alexa Girard

Myth Busters

Employment and Transition Services for People with Developmental Disabilities

By Brenda Considine

In this new feature in *People & Families Magazine*, readers are invited to submit questions about the service system for children and adults with developmental disabilities and their families. We invite questions about services across the life span, from early intervention services, to special education, to adult services, to estate planning. We will do our best to track down the answers from the officials and advocates who know, and publish them here as a resource for others. In this issue, we address the topic of employment and transition to employment.

MYTH #1: *While it might be helpful, school districts are not required to provide vocational evaluations as part of transition planning for students while they are still in school.*

FACT: Vocational evaluation is a necessary part of transition planning and, as such, is required. In fact, federal law (the Individuals with Disabilities Education Act—IDEA) states that “Beginning not later than the first Individualized Education Plan (IEP) to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include ‘appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills’” [§300.320 (b) (1)].

MYTH #2: *A student’s transition-oriented job sampling and work experiences should take place within the school building.*

FACT: Data shows that community-based, work-based learning experiences improve employment outcomes for students with disabilities. Just like the school requirement for placement in “least restrictive environment,” transition services must be provided in the least restrictive setting. Therefore, school districts

should look to community-based employment experiences first, and not to sheltered or self-contained work experience programs.

MYTH #3: *Because New Jersey is an “Employment First” state, competitive jobs in the community are the only option that can be considered for people with disabilities.*

FACT: We turned to the Association of People Supporting Employment First (APSE) for more information on what it means for New Jersey to be an “Employment First” state. “Employment First” simply means that employment in the general workforce should be the first and preferred option for individuals with disabilities who receive assistance from publicly funded systems. Typically, when it came to publicly funded services, employment in the community was among a number of choices presented to people with disabilities. Under “Employment First,” assistance with finding a job in the community and becoming a tax-paying citizen is recognized as the preferred choice.

“Employment First” starts with a presumption that a person with a disability can work and does not need to demonstrate their “readiness” for employment. If a decision is made that the individual won’t pursue employment, then other service options can be explored. It is important to remember that “Employment First” does NOT mean “Employment Only.”

Jennifer Joyce, DDD’s Director of the Supports Program and Employment Services, underscored this point.

“Employment is not the only option for individuals with intellectual and developmental disabilities, but it is an important option for individuals who are able to work independently or with supports. Being an “Employment First” state means that competitive employ-

ment should be openly discussed with every individual receiving services through DDD and that anyone interested in employment should have access to the services and supports available to find and maintain employment,” she said.

Myth #4: *Everyone, including those with significant medical and behavioral challenges is expected to be competitively employed in a paying job.*

FACT: According to Jennifer Joyce, employment goals are highly individualized. “Employment goals should be discussed with every individual if possible, but when an individual has a medical and/or behavioral challenge that prevents them from working, employment is not required.”

MYTH #5: *Services through the Division of Vocational Rehabilitation Services (DVRS) cannot be accessed until after a student graduates from high school or turns 21.*

FACT: DVRS services and supports are an important resource while students are still in school. According to a memo issued by David Free, Acting Director of the Division of Vocational Rehabilitation within the New Jersey Department of Labor, The Workforce Innovation and Opportunity Act (WIOA) of 2014 is “changing the way that services are provided, in particular for students with disabilities. WIOA emphasizes the provision of services to students and youth with disabilities to ensure they have opportunities to receive the training and other services necessary to achieve competitive integrated employment; WIOA also expands the population of students with disabilities who may receive services and the kinds of services that the VR agencies may provide to youth and students with disabilities who are transitioning from school to post-secondary education and employment.”

The agency is required to spend 15 percent of its budget on Pre-Employment Transition Services (Pre-ETS) for those ages 14 to 21 years old with an IEP or a 504 plan. Five discrete activities must be offered: 1) job exploration counseling, 2) counseling and guidance on training programs, 3) work-based learning experiences, internships, and apprenticeships,

4) workplace readiness training to develop social skills and independent living skills, and 5) instruction in self-advocacy.

MYTH #6: *Students with disabilities should accept a diploma from the local school district and graduate when they have met the credit requirements.*

FACT: Attorneys at Hinkle, Fingles, Prior, and Fischer remind us that many students with an IEP are eligible to remain in school through the school year in which they turn 21.

“They should continue to access all necessary transition services based on IEP goals and objectives, whether or not high school credits have been met. The IEP team—which includes the student and the parent—makes the decision about when a student should accept a diploma,” said Ira Fingles, Esq.

Once a student accepts a diploma, services from the local school district come to an end. If the student needs services from DDD, he or she could be waiting at home until age 21 for adult services to begin.

MYTH #7: *If people with disabilities want a good job, they should go to college.*

While college is an option for many people with I/DD, data show that rates of completion for college among students with disabilities are low, and many students end up taking remedial classes. Even for those who do finish, an advanced degree is not a promise of a job. Adults with a disability and a college degree have an employment rate of 59 percent—10 percentage points lower than all adults with a high school diploma or less, and 27 percentage points lower than all adults with a college degree.

MYTH #8: *The DDD Fee for Service system is the only way to get employment support services.*

FACT: According to Jennifer Joyce, individuals who are eligible for DDD can access Supported Employment, Career Planning, and Prevocational Training services through the fee for service system, but there are other options. Employment services offered by the

Department of Labor's Division of Vocational Rehabilitation Services (DVRS) must be accessed through DVRS before using DDD funding. If an individual is not eligible or no longer eligible for DVRS, DDD funding can be used instead. Non-employment services offered through DDD can be accessed at the same time an individual is accessing employment services through DVRS.

MYTH #9: *People getting DDD-funded supports have to be careful about how much they earn or they risk losing support services.*

FACT: Leaders at DDD confirm that individuals must maintain Medicaid eligibility to receive services from DDD, but there are programs that allow an individual to work without losing Medicaid benefits. Workability, NJ's Medicaid buy-in program, allows an individual to make more than \$5,000 per month or \$60,000 per year and still remain Medicaid eligible. In addition, the NJ ABLE program allows individuals to save money without jeopardizing Medicaid eligibility. It is recommended that individuals concerned about losing benefits due to work income contact the NJ Work Incentives Network Support program at www.NJWINS.org for benefits counseling.

MYTH #10: *There is a waiting list for DDD-funded employment programs and support services.*

FACT: DDD leaders confirmed that there is no waiting list for DDD-funded employment services in NJ.

DDD-funded employment services are available to eligible individuals based on their assessed needs, and include:

Career Planning

- A person-centered comprehensive employment planning and support service that provides assistance for program participants to obtain, maintain or advance in competitive employment or self-employment.
- A focused, time-limited service that engages a participant in identifying a career direction and developing a plan for achieving competitive, integrated employment.

- If a participant is employed and receiving supported employment services, Career Planning may be used to find other competitive employment more consistent with the participant's skills and interests, or to explore advancement opportunities in his/her chosen career.

Prevocational Training

- Provides learning and work experiences, including volunteer work, where the individual can develop general, non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings.
- May include training in effective communication with supervisors, co-workers and customers; generally accepted community workplace conduct and dress; ability to follow directions; ability to attend to tasks; workplace problem solving skills and strategies; and general workplace safety and mobility training.
- Intended to be a service that participants receive over a defined period of time and with specific outcomes to be achieved in preparation for securing competitive, integrated employment.
- Service is delivered in a face-to-face setting, either one-on-one with the participant or in a group.

Supported Employment—

Individual Employment Support

- Activities needed to help a participant obtain and maintain an individual job in competitive or customized employment, or self-employment, in an integrated setting.
- The service may be delivered for an intensive period upon the participant's initial employment to support the participant so they may sustain employment.
- The service may also be delivered on a less intensive, ongoing basis "follow along" where supports are delivered either face-to-face or by phone with the participant and/or his/her employer.
- Services are individualized and may include but are not limited to: training and systematic

instruction, job coaching, benefit support, travel training, and other workplace support services including services not specifically related to job-skill training that enable the participant to be successful in integrating into the job setting.

Supported Employment— Small Group Employment Support

- Services and training activities provided to participants in regular business, industry and community settings for groups of 2-8 workers with disabilities.
- Services may include mobile crews and other business-based workgroups employing small groups of workers with disabilities in employment in the community.
- Services must be provided in a manner that promotes integration into the workplace and interaction between participants and people without disabilities.
- Services may include but are not limited to: job placement, job development, negotiation with prospective employers, job analysis, training and systematic instruction, job coaching, benefit support, travel training and planning.

MYTH #11: *For those looking for a career path, such as adults with Asperger's, high functioning autism, or a history of college attendance, there are no job support services available.*

FACT: According to Jennifer Joyce, supported employment services can help an individual in both finding and keeping a job.

“This service provides an ‘Employment Specialist’ who will work as a job coach with the individual to identify a career path that matches the individual’s skills and interests, and provide support to complete resumes, attend interviews, and network

with potential employers to assist in finding a job,” she said.

Once an individual is offered employment, the Employment Specialist will provide on-site training to assist the individual in learning the duties of the job. The Employment Specialist will also arrange accommodations, modifications, assistive technology, etc., so the individual can perform the job as independently as possible.

“After an individual is stable at their job site, the Employment Specialist can continue to support the individual in maintaining employment,” she concluded.

MYTH #12: *New rules mean that sheltered workshops will be closing for good.*

FACT: Jennifer Joyce confirmed that there are no plans to close sheltered workshops. The Department of Labor and Workforce Development provides funding and oversight for sheltered workshops in New Jersey.

MYTH #13: *There are plenty of day programs for everyone who needs them.*

FACT: Parents report that for those who are medically fragile and have significant personal care needs, there are very few day programs. Leaders at DDD suggest that families contact DDD for assistance in identifying a provider to meet an individual’s needs. DDD is also actively recruiting new providers to serve individuals with I/DD, particularly providers that serve individuals with higher medical and behavioral needs.

Send your questions about the service system for children and adults with developmental disabilities and their families to njcdd@njcdd.org. We will do our best to find the answers, and publish them in future issues of *People and Families Magazine*. **P&F**

Resources

https://careerconnections.nj.gov/careerconnections/document/plan/Transition_Letter_For_Parents.pdf

New Lives: Closing North Princeton

COMMENT
Ethan B. Ellis

The bus lurched off I-95 and onto the back roads to North Princeton Developmental Center (NPDC). The lively conversation that had made the five-hour ride from Washington, DC, seem shorter also lurched to a halt.

We all felt the silence spread but no one knew how to break it and no one tried. It grew to a pall when we reached NPDC and stopped to let Tim off at Lakeside Cottage. The 12 of us could barely manage one good-bye. It was even harder to see Doug walk into the darkness toward SRU 12, leaving nothing but the crunch of his shoes echoing through the three-day-old snow.

Barry was in tears when the bus stopped at Morrow West. I asked Simon to go in with him so he wouldn't have to return to the locked unit alone. I needn't have. Simon was already putting on his coat. When he came back several minutes later, all he said was, "Jesus God!"

We had picked each of them up in a bus loaned to us by the Division of Developmental Disabilities (DDD) less than 36 hours earlier on the way to *Solidarity 2000* in Washington, DC, a national celebration of the increasing role that people with disabilities are playing in electoral politics. We were 12 altogether, seven more of us with disabilities and Simon Fulford, this magazine's photographer, and Jeff Bruce of the People's Support Network, both of whom had volunteered to drive the bus and help out where help was needed.

The three of them had made their lives real to the rest of us during that brief period. I will never forget Barry who holds the record for escaping from a New Jersey developmental center. I will never forget Tim, the ex-trucker's helper who has been to all of the lower 48 and earned \$22 an hour operating a snow blower at NPDC. I will never forget Doug who knew the year when Isaac Newton died and had a scholarship offer from Harvard.

The stories they told about their lives during our 36 hours together remain so real for a simple reason: If I had met them anywhere



■ This issue of PEOPLE WITH DISABILITIES is about closing North Princeton Developmental Center and the enormous success our community has achieved in accomplishing that task.

else, I could never have imagined any one of them living in a developmental center. Like so many who have lived in such places (and, sadly, most who still do), they simply didn't belong there. Like most of the others, they never wanted to be put there in the first place. A string of unfortunate circumstances took them there. Ever since, they have been waiting desperately for that string to unravel and lead them out to freedom again.

This issue of PEOPLE WITH DISABILITIES is about closing North Princeton Developmental Center and the enormous success our community has achieved in accomplishing that task. Barry and Doug and Tim have found their...

Position Statement on Deinstitutionalization

The New Jersey Council on Developmental Disabilities endorses the policy that, with proper supports, individuals with developmental disabilities, may be/could be capable of self-determination, independence, productivity and integration and inclusion in all facets of community life. It is imperative that future administrations be prevented from separating out those, who by the nature of their disabilities, may never demonstrate the aforementioned capabilities, with the purpose of re-institutionalizing them. The Council supports the declaration that:

Position

“People with intellectual and/or developmental disabilities (I/DD) have a legal right to live in the community and to receive necessary services and supports. Life in the community provides opportunities for dignity, freedom, choice, and a sense of belonging that are not possible in an institutional environment.¹”

“The State must provide all individuals living in institutions the choice of receiving the services and supports they need in the community. No one should be forced to live in an institution to receive critical services. DDD should continue its current practice of diverting admissions of individuals from developmental centers. Current residents of institutions who choose to remain, must continue to receive the services and supports that they require. Sufficient community-based services must be available so that institutional services will no longer be necessary.”

Background Information

“These truths are at the core of both the Americans with Disabilities Act (ADA) and the Olmstead decision. The courts have consistently upheld a person’s right to receive services in the least restrictive (most integrated) environment possible. Closing institutions is not about “dumping” people into the community, nor is it about closing large institutions and moving people to smaller institutions or institution-like settings. Closing institutions is about developing strong and inclusive community supports and allowing people to have control over how they live their lives.”

New Jersey continues to house individuals with I/DD in five large State-operated institutions (developmental centers). New Jersey spends 28% of its I/DD services budget on institutional care for a population that includes fewer than 5% of the individuals eligible for DDD services.² The cost of maintaining these institutions is often substantially higher than the cost to house individuals in the community. As the number of persons living in the institutions continues to decline, the cost per resident continues to increase. This limits the funding available to provide services and supports to individuals living in their communities. The State must shift needed resources to people living in their communities by formulating a plan to close and consolidate the remaining institutions as the number of the residents continues to decline.

Adopted by the NJCDD: February 13, 2019

¹ National Council on Disabilities website, 2018

² “The State of the States in Intellectual and Developmental Disabilities” 11th Edition 2017

Editor's Note: Ethan Ellis' legacy includes his staunch commitment to deinstitutionalization. He felt strongly that people with disabilities deserved fulfilling and productive lives in the community.

During the 80s and 90s Ethan's position on community living was viewed as controversial. For example, he felt strongly that individuals with intense behavioral challenges and significant medical needs could prosper in the community with adequate supports.

Today, many of Ethan's "so-called" controversial philosophies are commonplace nationally.

While I served as special assistant to the CEO, during the closure of North Princeton Developmental Center (NPDC), I had the pleasure of working with Gregory Fenton (former CEO, NPDC) to lead the effective and compassionate transition of more than 500 people with developmental disabilities to community-based settings. We were also charged with supporting the needs of more than 800 staff members who transitioned to other employment options.

During that time, Greg and I witnessed first-hand Ethan's political savvy and strong operational influence. We had no doubt that he was advocating for the best interests for people with disabilities.

It is a very fitting tribute to honor Ethan's grrrrreat legacy while the NJCDD unveils its updated Position Statement on Deinstitutionalization.



*Gary L. Brown
Editor,
People & Families Magazine*

G. Brown at NPDC circa 1994

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Ethan Ellis attending the ADA March with Bob Kafka on July 26, 2005.