

# People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

WINTER 2017

## FILM ACADEMY 360

State-of-the-Art Media Production  
Training for Students on the  
Autism Spectrum

Vincent Lissandrello and David Di'lanni  
(standing) teaching video editing to Tyrell  
Dickerson at Film Academy 360.



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For People with  
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### The Importance of Choice

When looking ahead in 2017, one of the best New Year's resolutions we can work toward is the idea of "choice". As a Council, we resolve to work hand in hand with advocates and family members to push for increased choice—in housing, in support services, in employment, and more—for individuals with developmental disabilities in New Jersey. We hope you'll join us.

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As a trained dancer, a certified special education teacher, and a fierce advocate for her two sons with developmental disabilities, Joanne De Simone is woman with many talents. Along the way, she's honed her skills as a writer, and is currently working on a memoir chronicling her life lessons as a mother, daughter, wife, advocate, dancer, and special education teacher.

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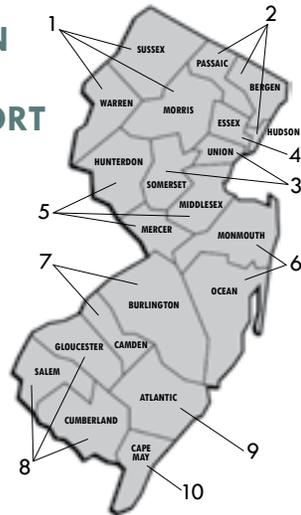
## 20 CHOICES AND CHALLENGES

### Support Coordination in New Jersey

Since 2014, the NJ Division of Developmental Disabilities has been administering services to families with the help of Support Coordinators. Differing from the Case Managers used in DDD's old system, Support Coordinators are meant to provide more involved assistance to the individuals and families they serve. However, many families have not found the transition to this new system to be as smooth as they'd hoped.

Cover Photo  
Vincent Lissandrello and David Di'Ianni  
(standing) teaching video editing to Tyrell  
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—Photo by: Rebecca Shavulsky

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### The Challenges and Rewards Of the Direct Support Profession

With low wages, high job turnover, and challenging work environments, the direct support profession isn't one for the faint of heart. Many long-term DSPs hope to stay in their field because of a love of helping people and a deep connection to those they serve. However, perhaps the greatest challenge that many DSPs face is finding a way to earn a living in this critically needed profession.

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### The Forgotten Minority

Making up roughly 19% of the population, people with disabilities are the largest minority group in America. However, they generally haven't been acknowledged as such by politicians or the public. In this writer's opinion, this is due to the way people with disabilities are viewed under the law.

from the Council Chairperson ■

## The Importance of Choice

The new year is a time to reflect, a time of renewal, and a time for resolutions.

It is encouraging to look back over the past year's accomplishments, which demonstrated the proof of the power of our collective voices. Our efforts were clearly evidenced in the changes reflected in the Home and Community Based Services Waiver. Although at times anxiety may have run high, it was in the true spirit of partnership that we were able to come to the table to provide a clear understanding of our concerns. This allowed for real conversations to shape components of the waiver to better support individuals with the supports they need to live successfully at home and in the community.

As we begin this new year, we can renew our commitment to collaboration by continuing to channel our efforts to work with the Division of Developmental Disabilities (DDD) and other advocacy organizations. This will ensure that we represent the needs of all individuals throughout the state. I am excited that we were able to help facilitate the creation of the Family Advisory Committee (FAC), along with the Regional Family Support Planning Councils (RFSPCs) and Assistant Commissioner Shea. This committee will provide a setting to have all our voices represented throughout the state. This was an opportunity for us to utilize the RFSPCs, which were established in 1993 as a result of the *Family Support Act*. The formation of this committee is an initiative that allows us to use the support structures already in place and enhance their presence instead of creating yet another group. The committee will meet with the division leadership regularly to provide input and feedback on DDD systems and services. The RFSPC for each county will have a seat on the FAC so that all counties are able to stay well-informed on potential changes, current challenges, and provide feedback on how these impact their loved ones living in the community. It is important that you consider joining the RFSPC for your county so that we can expand our informational and advocacy efforts.

If we had to find a common resolution for the new year, I think we should consider 'choice.' When I consider the ideals that illustrate independence,

individuality and respect for me as an individual, it is that I have the right to choose. I can choose who I live with, what neighborhood I live in, what type of house I live in, how I spend my time, where I work, how I dress, what I eat, who I call friends and, most importantly how I define happiness, success, and independence. It is human nature that we want the best life for our children, so I would never accept less than that for my children just because they have a disability.

According to Dictionary.com, there are several definitions for the word choice. These are the two I think clearly define my description of choice: *the right, power, or opportunity to choose; an abundance or variety from which to choose*. If we use these definitions as the core when creating the support structures an individual needs to build their life, the outcome will be person-centered. We need to resolve to advocate towards maintaining an individual's power to choose, but it is equally important to be open to creating the variety from which to choose. There can be no cookie-cutter solutions but rather conversations that determine an individual's definition of happiness, success, and independence. That leads us to the responsibility to work together to use resources to create that person's vision for their life.

As the Council begins 2017, we are also beginning our new five-year plan. Our new goals and objectives have been set to include focusing on self-advocacy, family training and information, direct support staff, special education, employment, transportation, health and wellness, and housing. Through the process of developing the five-year plan, council members concluded that these were the areas of priority. As we move forward with implementing the five-year plan, we need to focus on the how we can build capacity of choice for individuals as we address these areas. The next five years are filled with tremendous opportunity. If we continue to work collaboratively and expand our reach of self-advocates, members and families, we can have a tremendous impact on the future. Real choices require real effort and real collaboration.

—Stephanie A. Pratico  
Council Chairperson

*The NJ Council on Developmental Disabilities*

## In Memorium Michael Augustowicz



### Dedicated Advocate, Cherished Friend

Earlier this fall, the New Jersey Council on Developmental Disabilities was saddened to hear of the passing of one of New Jersey's dedicated disabilities advocates, Michael Augustowicz.

A resident of Dumont, NJ, Augustowicz worked tirelessly to advocate for New Jersey's disabilities community for many years. Leading the NJCDD's Monday Morning advocacy group in Bergen County, he

worked along side his fellow members to make real changes in his community. Among his many accomplishments included pushing for increased accessibility at the Izod Center in the Meadowlands Sports Complex, and helping to pass a law requiring all vehicles carrying passengers with disabilities, including ambulances and other medical transport vehicles, to use a three-point safety belt for wheelchairs and scooters.

All comments can be sent to the NJCDD's Communications Manager,  
Jonathan Waller, at [jonathan.waller@njcdd.org](mailto:jonathan.waller@njcdd.org)

Michael continued his work as the NJCDD's Monday Morning network transitioned into People First New Jersey, once again taking the lead in organizing advocates throughout Bergen County.

On his own, Augustowicz volunteered regularly at the Bergen Regional Medical Center (BRMC) in Paramus, creating and planning activities, and providing opportunities for BRMC residents to volunteer within their community.

In 2010, the Health Care Association of New Jersey honored him with their Volunteer of the Year Award for his significant contributions to the quality of life for long-term care residents.

Michael also worked part-time at Heightened Independence and Progress, a Center for Independent Living, where he helped transition BRMC residents who were eligible to move into the community.

Michael's life and work were also highlighted in the Spring 2015 issue of *People & Families Magazine*.

At a memorial service held on Friday, November 18, NJCDD staff joined Michael's family, friends, colleagues, and fellow advocates at the Bergen Regional Medical Center to celebrate his life and the positive impact he had on those whose lives he touched.

## New Law Expands Access To Special Needs Trusts

By: Michelle Diamant

From: DisabilityScoop.com — December 16, 2016

Tucked inside a larger bill signed by President Barack Obama is a tweak to federal law that's designed to make it easier for people with disabilities to save money.

Under the new law, individuals with disabilities can create a special needs trust for themselves rather than relying on others to do so.

Previously, such trusts needed to be established by a parent, grandparent, legal guardian, or a court.

The change outlined in a bill known as the *Special Needs Trust Fairness Act* was approved unanimously by the US Senate last year and passed the House of Representatives in September.

But due to some differences in the House version, the measure returned to the Senate and

was ultimately bundled within the *21st Century Cures Act*, which Obama signed on December 13.

The option for people with disabilities to create their own special needs trusts takes effect immediately.

"This provision replaces an antiquated law that was unfair and outmoded in its treatment of people with disabilities," said Sen. Chuck Grassley, R-Iowa, who sponsored the *Special Needs Trust Fairness Act*.

"Those who want and need to set up a trust to help pay for their care should be able to do so, plain and simple," Grassley said. "This measure allows individuals to act in their own interests with their own assets without having to rely on a family member or the courts."

# Allendale to Assist Nonprofit With Land Purchase

By: Sarah Nolan

From: NorthJersey.com — December 14, 2016



Easter Christian Children's Retreat is seeking to purchase a home at 200 West Crescent Avenue in Allendale and convert it into a five-bedroom group home.

The Allendale Borough Council wants to contribute \$20,000 toward the purchase of 200 West Crescent Ave., where a nonprofit organization plans to build a five-bedroom group home for adults with developmental disabilities.

The governing body is seeking permission from the state Superior Court to release the money from the borough's affordable housing trust fund.

The borough would receive five credits toward its yet-to-be-decided affordable housing obligation should the contribution be approved, Mayor Liz White said at a recent council meeting.

Towns across the state, including Allendale, are awaiting a state Supreme Court decision regarding whether municipalities must build low-cost housing units to cover a "gap period" of 17 years, from 1999 to the present, when the

Council on Affordable Housing, or COAH, was inactive due to bureaucratic dysfunction. At stake is the difference between building roughly 100,000 affordable-housing units in the next decade, or 200,000.

The asking price for the property is \$420,000. The nonprofit, Eastern Christian Children's Retreat, will spend \$400,000 of its own funds to acquire the site, Executive Director Jayne Press said. Press said the nonprofit plans to apply for other funding opportunities toward the purchase in the spring.

The home will be Eastern Christian's second in the borough. The nonprofit, which serves more than 120 individuals with intellectual and developmental disabilities according to its website, also has a five-bedroom home at 135 West Crescent Avenue.

Press said a contract for purchase of the site is being drawn up. The organization plans to demolish an existing home on the property and build a new, handicap-accessible home.

Press said the close proximity of the two homes will help with staffing and supervision. Construction will likely start in the fall of 2017.

“We’re thrilled that Allendale is so willing to help us out,” Press said. “The town has been a supportive community for us, and very welcoming since we opened our first home in June.”

Allendale plans to submit an amended affordable housing plan to the state that includes use of the \$20,000 in affordable housing funds.

Also included in Allendale’s amended plans is

the withdrawal of \$325,000 from the fund toward the acquisition of 220 West Crescen Avenue, where the creation of age-restricted affordable rental units are planned.

The town recently announced it reached an agreement to purchase 220 and 230 West Crescent Ave. from West Crescent Realty, LLC for \$13.75 million. Along with affordable housing for seniors, borough offices and recreation or park space are planned for the 9.7 acre site.

The borough’s affordable housing trust fund currently has a balance of \$406,653, White said.

Borough Attorney Raymond Wiss will go before the court on Jan. 6 to seek approval of Allendale’s new affordable housing plan, as well as withdrawal of the trust fund money.

The New Jersey Council on Developmental Disabilities

## Want to Become a Council Member?

To recommend yourself or someone else to be a member of the Council, follow the steps below:

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- On the top, blue tab, choose → Government
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Follow the instructions for submitting the required information, and be sure to include that you are interested in becoming a member of the New Jersey Council on Developmental Disabilities.

**Or contact the Governor's Appointments Office:**  
 Phone: 609-777-0251 Fax: 609-777-0331

**Council Members are appointed by the Governor. Membership is open to New Jersey residents who have a developmental disability or are immediate family members of someone with a developmental disability.**

**Council members review the state’s service systems for people with developmental disabilities, advise policy makers on the best ways to change those systems to better serve the population, and promote the goals of the federal Developmental Disabilities Assistance and Bill of Rights Act. Members review and award grants to spark innovative projects throughout New Jersey. The Council and its individual members also advocate for people with developmental disabilities and their families on an on-going basis.**

**For more information about the Council visit our web site: [www.njcdd.org](http://www.njcdd.org)**

# Sen. Shirley Turner: Require Aides On School Buses Following Trenton Attack

By: David Foster

From: The Trentonian — December 13, 2016

The bus that a four-year-old Trenton preschool student was attacked on was without an aide.

Following a *Trentonian* report about the assault that occurred in early December that left the student with disabilities with a busted nose, swollen face and a possible concussion, State Sen. Shirley Turner (D-Mercer/Hunterdon) is proposing legislation to require the placement of aides on school buses for special needs students.

“The children’s safety has to be paramount,” the long-time 15th district legislator said Tuesday in a phone interview. “You can’t expect for a school bus driver to be able to focus on the road while operating the school bus, and then at the same time, be concerned about the discipline problems that’s going on behind him on the bus with children of all ages, and also children with special needs. That’s a disaster waiting to happen.”

Last week, the boy’s parent told *The Trentonian* that the 4-year-old rides on a bus with students as old as 10 or 11 with no aides, and she’s been complaining for weeks about her son’s safety, but the district has done nothing. The mother also contended that the bus driver would not separate the fighting students because they are not allowed to touch the kids.

To make matters worse, the district was obligated by the boy’s Individualized Education



State Senator Shirley Turner (D-15)

Program (IEP), a plan for each special education student, to provide a bus aide, Nicole Whitfield, executive director of the Special Parent Advocacy Group, said Tuesday.

The student rides a regular-sized bus in the mornings and takes home a small bus, but “there were no aides on either bus,” the advocate said.

“The student’s IEP called for an aide on the bus, so they violated the student’s IEP,” Whitfield said. “The district is violating IEPs by not providing the aides at all. And then, other

times, they’re putting too many kids on the bus and not putting enough aides.”

Turner had actually introduced the bus aide bill in November following another *Trentonian* story of an 8-year-old special needs girl who was allegedly sexually assaulted on a bus in July. A male student exposed himself and forced the young girl’s head into his private area, multiple witnesses told the newspaper.

Whitfield approached Turner claiming there was not enough supervision on the buses for special needs students.

For the alleged sex assault, there was one aide on the bus for approximately 40 students, Whitfield said.

“Trenton tends to put all of our special needs kids on one bus, especially in the summer,” the

advocate said. “In the summertime, you can have 40 to 45 kids with disabilities on one bus and one aide.”

The problem, Whitfield said, is state code does not place a cap on the ratio of students to aides for transportation.

“Legally, they’re not violating any type of code for the case that happened in the summertime,” Whitfield said. “However, if there’s a ratio in the classroom, then there definitely should be a ratio on the bus. Most districts utilize better judgment and they utilize common sense where they will just use small buses to transport special needs students. Trenton will use large buses and put one aide on the bus for 40 to 50 kids.”

Turner’s bill would require one bus aide for every 15 special education students.

“The problem that I was able to discern during my conversation with the superintendent,

I think the problem is funding, which is always the root of many of the problems in the urban districts, particularly districts like the city of the Trenton,” Turner said, noting the district is \$20 million underfunded based on the school funding formula. “They just don’t have enough money in order to cover their expenses.”

Trenton Public Schools has sustained numerous budget shortfalls in recent years, resulting in massive layoffs, privatization, and school closures.

Turner feels the district is “already cutting into the bone marrow” and is “between a rock and a hard place.”

“I think one way that they cut those expenses is by reducing transportation because that is very expensive,” the senator said. “I think we need to make sure that the safety of the children is first and foremost.”



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# Rutgers Neuroscientist Identifies 'Ignored' Symptom of Autism

By: Kathleen O'Brien

From: NJ.com — December 12, 2016

A Rutgers neuroscientist who examined MRI images of more than 1,000 people with autism now says a constant stream of involuntary “micro-movements” throughout the body are a core symptoms of the disorder.

These unusual motor patterns continue to exist even if the patient is medicated, Associate Professor of Psychology Elizabeth Torres writes in an article about her research. Her research was published recently in Nature Scientific Reports.

“The person doesn’t even know they’re doing it. And they may not be visible to the naked eye,” she said. “But they end up interfering with the nervous system because they’re random noise.”

The problem shows up even if the person is taking medication for autism symptoms, she said. While medication helps in some cases, it can also make the problem worse, she wrote.

Torres said does not believe the movements cause autism but sees them as symptoms worthy of investigation.

Torres, who specializes in sensory-motor integration research, said she stumbled upon a treasure trove of data when talking with a colleague about MRIs of the brain.

Anyone who has ever had that procedure knows the patient is instructed not to move.

“But that’s impossible. Everybody moves. We breathe, we have a heart beat, digestion - that’s all motion,” Torres said in recounting her perplexity. She learned that evidence of micro-movements is routinely scrubbed from images to eliminate any blurs they cause.

She next looked at the scrubbed data—the very stuff usually discarded—for more than 1,000

MRI patients who had an autism diagnosis.

She discovered they show far more motion that normal—a nearly constant barrage of signals that can overwhelm the brain. That matches what autism patients have told her over the years: “It’s as though my body has a mind of its own. When I tell my body where to go, it takes the scenic route. It takes my body too long to get there.”

Her response is, “It’s not that you’re dumb. It’s that you’re trying to do what a typical person’s brain does so quickly.”

The research has gotten some attention in the field of autism research because it focuses on bio-rhythms instead of genetics or behavior, she said.

“Science is stuck in researching what is the cause of autism,” she said. We should be asking, ‘What can we do to improve the lives of these people?’”

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## Sweeney Tours Abilities Solutions, Gets Firsthand View of Employment Program For Those With Disabilities

From: NJ Senate Democrats — December 8, 2016



NJ Assemblywoman Patricia Egan Jones and Senate President Steve Sweeney tour Abilities Solutions in Westville, NJ.

Senate President Steve Sweeney joined with Susan Perron, President and CEO of Abilities Solutions, Assemblywoman Patricia Egan Jones, and representatives from ACCESS New Jersey to tour the Abilities Solutions facility in Westville, New Jersey, which helps provide transitional and extended employment opportunities to individuals with developmental disabilities.

“Having meaningful employment not only provides economic freedom for individuals with disabilities and allows them to learn new skills

that will help them in their daily life, but it also instills a great sense of pride and fulfillment,” said Senator Sweeney. “Abilities Solutions recognizes this and helps remove barriers to employment by identifying job opportunities and matching individuals to suit their needs. I applaud the community and the businesses that partner with one of South Jersey’s valuable resources.”

Abilities Solutions was founded in 1963 as the Occupational Training Center of Gloucester County by a group of parents who knew that

their children would benefit by having the ability to work. The center now serves between 700 and 800 people with disabilities or other disadvantages each year and works with over 200 South Jersey employers to match workers with jobs in the business community and at the center.

“While some individuals may do better working at local businesses, center-based work may be more suitable for others. There is no one-size-fits-all solution,” said Assemblywoman Egan Jones. “Abilities Solutions has a successful formula that works for the people they train and employ and for the businesses and the community that benefit from dedicated and productive individuals.”

“By working with public and private sector partners, the center can provide opportunities for both individuals and employers to find success,” said Gloucester County Freeholder Director

Robert Damming. “That’s why it is important for the business community to be engaged with centers like Abilities Solutions. It’s a win-win for everyone.”

“I want to thank our elected officials for recognizing the importance of our work in the community to help youth, adults and veterans with disabilities and other disadvantages find meaningful employment. With their support, we can continue to build relationships to fulfill our mission and serve our community,” said Perron. “In particular I want to acknowledge Senator Sweeney’s leadership on passing SJR68, which recognizes the value of every employment option for people with disabilities. In doing so, he positions NJ as the champion for our most vulnerable and sets the standard for other states to follow.” **P&F**

New Jersey Council on  
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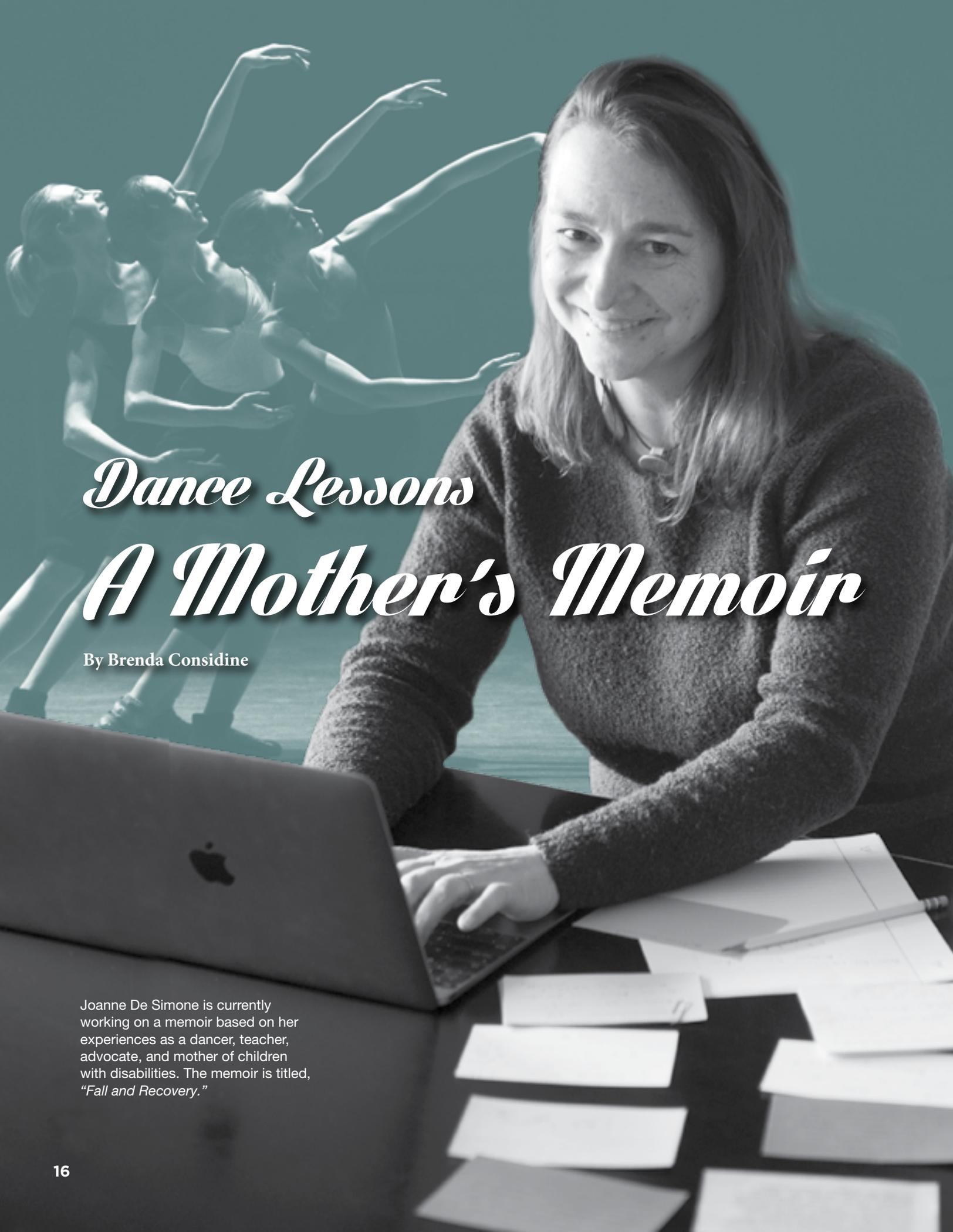
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# *Dance Lessons A Mother's Memoir*

By Brenda Considine

Joanne De Simone is currently working on a memoir based on her experiences as a dancer, teacher, advocate, and mother of children with disabilities. The memoir is titled, "*Fall and Recovery.*"

# *“We live our lives infused with love and grief, one hundred percent of the time.”*

—Joanne De Simone

Joanne De Simone is not afraid of telling the truth. She is also not afraid to laugh out loud at the absurd and the tragic.

A self-proclaimed “creative,” the Brooklyn-native has been writing poetry since she was in high school as a way to express and manage feelings around the sudden loss of her father, who died on the morning of her older brother’s wedding when Joanne was only 9. In college, she became a student of modern dance, and traveled through Europe as part of a dance troupe. Later, she turned to essays and poetry to share the complex emotions of parenting two boys with disabilities.

Now, Joanne is writing a memoir, braiding together all she has learned as a mother, daughter, wife, advocate, professional dancer, and special education teacher.

The process of writing a memoir has been described as transformative, soul-bearing work, giving voice to a past that will not remain silent. It can be raw, funny, powerful, and vulnerable. But most of all, it is about telling the truth.

In one of her first published pieces, Joanne exposed one such excruciating truth. In her essay *Bury My Son Before I Die*, she writes:

*“It goes against everything we believe about motherhood, but I’d rather bury my child than leave him behind...”*

*If orphaned, Benjamin would need to live in some kind of hospital facility... I picture Benjamin alone in a bed, hooked up to tubes, nothing more than an insignificant number on a chart. With that in mind, I’d rather see him dead.*

*I have learned to embrace motherhood with brutal honesty. I don’t actually want to see my son take his last breath. I don’t want to know life without him. For as long as I live, I will do whatever I can to keep Benjamin healthy and give him the best*

*possible quality of life. His happiness is my happiness. He is no less than anyone else, deserves every right and consideration.*

*As Benjamin’s advocate I can guarantee a strong proactive force. When I’m gone, I can do no more.”*

Joanne was surprised by the response she got: the magazine’s editor-in-chief loved it and didn’t change a word. It opened the door to a live interview on *The Huffington Post*. Even more unexpected was the flood of parents of children and adults with profound disabilities who responded to the essay, confessing to the fear of dying before their children.

“I thought there would be backlash—hatred—but there was none of that,” said Joanne. “Instead, I heard from parents across the globe who felt the same way; mothers who thought they were monsters for thinking that.”

“I am writing a memoir because I know I have to talk to others on this journey. I simply want to share my unapologetic truth,” she said.

## *Early Lessons*

In her early twenties, Joanne studied at Hunter College in New York, where her love of modern dance was born. There, she was trained as a professional dancer and was introduced to the work of José Limón, a pioneer in modern dance and choreography. After graduating, she performed with the troupe on a tour through Poland, Czechoslovakia, Yugoslavia, and France. When she returned to New York, she had the unexpected opportunity to pursue her one true dream—she auditioned for a highly competitive ongoing position with the dance company. She did not get the position, and while that day brought to a close her dance career, it did not erase the lessons she learned on stage and in rehearsals.

“Dance taught me not only how to move freely through pain, it taught me how to fall and recover,” she said.



(from right to left) Joanne De Simone at home in West Orange NJ with her sons Sebastian and Benjamin and her husband John.

Although she did not know it at the time, she would need those lessons later in life.

In 1993, she married her husband John and returned to Hunter College to pursue a master's degree in special education. The couple dreamt of living, working, and raising a family in Brooklyn.

Since then, Joanne has committed most of her adult life to special education, first as a certified teacher, then as an advocate and the mother of two sons, both with disabilities.

She admits that nothing—even her training as a special educator—prepared her for the birth of their first son, Benjamin. Born with lissencephaly, a life-limiting condition that causes cerebral palsy, Benjamin has multiple seizures a day, uses a feeding tube, a wheelchair, and communicates solely with facial expressions and vocalizations. He has undergone numerous surgical procedures to address bone and spinal issues.

“Professors don't lecture about watching your seven-month old suffer two hundred seizures in one night, failed medication trials, or the routine deaths of children in your support group,” she said.

She and John wondered if they would make it through, but several years later, Joanne gave birth to Sebastian.

“After Ben, I think our friends and family wanted John and I to have ‘closure’—what ever that is,” she laughed. “I wanted to experience parenting without all the medical drama.”

But as Sebastian got older, it became clear that he was not developing as expected.

“I think John and I knew instinctively that Sebastian had developmental delays along the autism spectrum,” she recalled, “but coming to acceptance was more of a struggle the second time around.”

In 2008, the couple left their home in Brooklyn to come to New Jersey in search of quality special education services for their sons.

### *Making Time to Become a Writer*

Joanne first started sharing her parenting experiences when she was invited to speak to a group of college students in New York.

“I kept hearing the same thing: ‘you should write a book,’” she said.

So about five years ago, she began writing. Knowing her manuscript was not ready for publication, she tabled it for awhile and started writing essays with the hope of getting them published, and building a platform worthy of an agent's attention.

Her first publication came in 2013 when *The Huffington Post* issued a public call for submissions on the topic of “the moment I knew.” She submitted an essay about a dramatic moment of judgment and confrontation in a Brooklyn pharmacy that marked the moment she knew that she and her family had to leave New York City in order to find the sense of belonging her family needed.

The piece was accepted within hours, and her work has since appeared in *The Washington Post*, *The Huffington Post*, *Brain*, *Child Magazine’s Blog*, *Literary Mama*, *The Mighty*, and *Common Ground*. She blogs at <https://special-education-mom.com>. She is a 2016 BlogHer Honoree and a contributing author to *Barriers and Belongings: Personal Narratives of Disability*, forthcoming from Temple University Press.

Joanne is busy, but believes that her schedule and pace actually helps. She sets daily and weekly goals and writes at night after her boys go to bed, when they are at school, or on weekend mornings before her family wakes.

“I am super-structured and get more accomplished when I have too much to do. Working around the boy’s needs forces me to use my time efficiently,” she said.

“Oh, and I don’t go out for mani-pedis...” she joked. “This is what I do. Writing IS my only outlet.”

## *The Book*

As a new writer, Joanne knew she had a lot to learn. She’s been taking a series of ongoing writing workshops for several years, connecting her to other writers and editors. With their guidance, she learned how to structure her story and connect her ideas. She has also learned about the business of getting published, and has written a detailed proposal for agents and publishers to consider.

The memoir, titled *Fall and Recovery*, traces her journey “from lost dreams of being a dancer, to a life of purpose.” The memoir is framed around three “Acts” and leverages different ‘long forgotten dance lessons’ that Joanne has applied over the years to parenting, even without her own realization.

She is quick to emphasize that her book does not fit the mold of other disability memoirs or books on special needs parenting.

“The world doesn’t need another book about an ‘exceptional miracle’ or about ‘the honor and courage’ of being the mother of a child with disabilities,” she joked.

Joanne believes that parents of children with disabilities are often marginalized. She hopes that her memoir will “remind us that the world is full of children like ours, and parents who are constantly managing the fluid dance of acceptance.”

While aimed at parents, extended families, medical professionals, educators, and dancers, Joanne hopes her book will find a wide audience.

“This book is for anyone who thinks their lost dreams were a waste of time,” said Joanne. “Whatever your training and preparation has been, it belongs to you.”

“Surviving motherhood is not a matter of bravery or strength, it is a matter of linking your past experiences and creating purpose in your own life. It is recognizing that we live simultaneously in love and in grief.” **P&F**

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De Simone has kept memorabilia from her early days of professional dancing.





# Choices and Challenges

## Support Coordination in New Jersey

By Brenda Considine

Eleanor Bracey is quick to admit that she did not have high expectations for her daughter Laura's easy and swift transition from school to adult life.

"Usually, anything having to do with the government is slow, and I had heard nightmare stories about accessing adult services," she confessed. "We were one of the first families in the new supports system, so I was expecting problems."

But Laura's transition was seamless. Before graduating in 2015 from St. John of God, a private school for students with disabilities, Laura and her family worked with a support coordinator from Values Into Action. Together, they developed a person-centered plan for Laura, and then identified and selected her services and supports, including those offered through nearby HollyDELL. There, she is working on building independence, interests, job readiness, and communication skills so that she can one day have a job working with children.

"I expected Laura to be home all summer, but she didn't miss a beat," said Bracey.

According to the National Association of State Directors of Developmental Disabilities Services, both 'case management' and 'support coordination' are a fundamental lynch pin in any system. There are similarities, but there are fundamental differences.

Support coordinators do not simply arrange government-funded services. Rather, they function more like a guide, listening and responding to the preferences and needs of individuals with disabilities and their families. They help individuals plan for the future they want, and get connected to the services and resources they need so they can build a meaningful life in the community. (See box for more)

In Laura's case, that meant working with Access Link to arrange door-to-door transportation, and a Saturday respite program where she

gets support attending community events. It also meant her family looking to natural, unpaid supports in the community. Laura is involved with SPANNER, a social group for those with disabilities, and goes to movies, dances, and shows several times a month at St. John of God, where she attended high school. She is also active with her church.

### **New Conversations, New Choices, New Challenges**

According to Heather Cooper, Resource and Development Director at Values into Action, for individuals and families who are used to a traditional case management approach, support coordination offers “a very different conversation.”



The goal of Support Coordination is to help individuals with disabilities to achieve the highest possible quality of life.

## **The Role of Support Coordination in DDD’s Supports Program**

While new to many, Support Coordination has been in place in New Jersey for more than a decade, as part of several initiatives aimed at supporting people with disabilities in the community as they left institutional settings. Starting in 2014, under the Division of Developmental Disabilities (DDD) Medicaid-based, fee-for-service system, all individuals who are eligible for and wish to access DDD-funded services must work with an approved support coordination agency.

Support Coordination is a service that assists individuals with disabilities and their families in accessing programs and services, as well as medical, social, educational, and other services.

Support Coordinators use a person-centered planning process to identify outcomes, and plan goals and supports for an individual with disabilities. They develop and maintain the Individualized Service Plan (ISP), and help the person with disabilities and his/her family find supports and services through a combination of traditional disability providers, generic community supports, government supports

beyond DDD, and natural supports in the community, workplace, or home. They also conduct ongoing monitoring of the provision of services included in the ISP, make monthly contact with the individual, and respond to emergencies and other service-related needs of the person and/or family.

The Supports Program is the cornerstone of a DDD initiative that is part of a new Comprehensive Medicaid Waiver (CMW). It provides supports and services for adults with developmental disabilities who are living with their families, or in other unlicensed settings. Participants and their families can choose the employment/day services and individual/family support services they want, using a budget that reflects their identified needs.

The Supports Program was designed to better serve adults with developmental disabilities, and to reduce the number of individuals waiting for supports and services. In addition, it allows New Jersey to receive millions in Medicaid funding—for every dollar spent on the program, half comes back to the state in the form of Medicaid funding.



Laura Bracey (Center) works with staff and her fellow program members at HollyDELL to build independence, interests, job readiness, and communication skills.

“We are not case managers. This is not about simply lining up DDD services. We look beyond the social service system—helping people coordinate unpaid services too. We want to help them build something that is sustainable and that makes them part of the community,” she said.

She believes that traditional service models were based on the assumption that a shared disability label was enough to create and maintain connections.

“The idea was, ‘if you have autism, you will naturally want to hang out with other people who have autism.’ But connections need to be based on friendships, interests, and goals, not disability,” she said.

“We find that when you ask the right questions, and have the right conversations, people have rich lives outside of disability—we begin with helping people see the connections, not the limitations.”

One of the biggest changes that comes with supports coordination is choice. Individuals and their families may now choose the agency they want to help them plan for—and obtain—the supports and services they need.

In New Jersey, there are nearly 80 support coordination agencies. Some offer services

statewide, others, just in a small part of the state. So just how does an individual and family pick a support coordination agency?

Lisa Ford, director of The Arc of New Jersey’s Family Institute advises families to do their research, talk to other families, and meet with the agency before making a selection. She encourages families to ask questions of several agencies in order to compare them.

“Families should know how long the agency has been qualified by DDD to provide support coordination, and whether the agency has authority to approve service plans and other

paperwork,” she said. “And if you leave a message and don’t get a call back within a few days, it is a sign that the agency might not be responsive,” she cautioned.

Along with new choices, there are new challenges. While families can choose the agency they want to work with, they are typically *assigned* to a specific support coordinator.

For Yolanda Smith, the process of getting to the right agency and the right coordinator has been an odyssey. She has been with four different support coordination agencies and has had 12 different support coordinators.

“People would start, then they would quit,” she said. “I would get these phone calls, ‘Hi, I am your new support coordinator,’ then a few weeks later, a new voice with the same message, ‘Hi, I am your new support coordinator.’”

The process took a lot of Yolanda’s time, and paperwork errors made by inexperienced support coordinators caused Yolanda’s daughter, Antonia to lose money in her budget.

Today, Antonia receives support coordination services through Disability Services and Advocacy. “They are very professional and accurate, and if I have a problem, they get answers for me right away,” said Yolanda. “I am very pleased.”

The system allows individuals and families to change support coordination agencies every 30 days. The Family Institute is one of the places families turn when the system is not working as expected.

“We hear from many families about high rates of turnover for support coordinators within agencies,” said Ford. She also said some families are frustrated by delays that occur when newer agencies cannot approve their own service plans.

Ford’s office also gets calls from support coordinators looking for help. “Whether it is a lack of training or simply that the system is so new, we find that some support coordinators do not know the system and what resources are out there,” she said.

## A System in Transition

Mercedes Witowsky and her daughter are working with a support coordinator, and as Chair of The Statewide Family Support Planning Council, she also hears from a lot of families.

“When the Family Support Planning Council surveyed families about the supports program last year, many of them did not know about the systems change, and did not know if they were in the system or if they qualified. That is still a problem.”

Rebekah Novemsky, a parent and Vice-Chair of The Statewide Family Support Planning Council said many families simply cannot get the services

*“We find that when you ask the right questions, and have the right conversations, people have rich lives outside of disability—we begin with helping people see the connections, not the limitations.”*

—Heather Cooper,  
Resource and Development  
Director at Values into Action

they need, particularly transportation, even when it is a service in the person’s plan.

That is the case for Yolanda. Since Antonia graduated from Gateway School in Carteret three years ago, Yolanda has been working with her support coordinator to get transportation to and from Antonia’s adult day program. In spite of years of efforts and many false starts, Yolanda drives her daughter back and forth.

“It is a an hour and fifteen minutes round trip, twice a day. This would be reimbursable, but not to parents. I am stressed out, and I am not the

only one with this problem.” she said.

Rebekah adds that accessing services across state systems is also a major challenge, especially if the issues involve mental health.

Kathleen Whelan Ferris knows about this challenge first hand. Her 25-year-old son, Luke

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Laura Bracey at her Mt. Ephram, NJ home with her mother Eleanor.



Mammel, has been receiving support coordination services since he graduated from Y.A.L.E. School's Standard 9 program in 2012.

"In addition to autism, Luke has mental health issues—anxiety and panic disorder. He is very naïve and lives a protected life because he does not have the social intuition to solve problems for himself."

She believes that the supports system built around her son largely ignores this, and does not reflect the full scope of his needs. And like many other families, they have experienced a high rate of turnover in support coordinators.

Yolanda readily admits that she is "not a

fan" of the system and does not expect things to improve.

"I am not alone when I say I don't have much hope that things will get better," she said. "To be honest, I am a different person than I was in 2013. At 25, Antonia is much more dependent on me now than when she was in school. Day-to-day, I am never sure what will happen," she said. Others remain far more optimistic.

Cooper noted that the supports program is increasing access so people can build community and social capital. She believes that the program is yielding a lot of jobs and connections, but people have to be patient.

Luke Mammel's dream—his one true wish—is to run a music program for preschoolers. The 25-year-old self-taught musician plays guitar. He also plays the clarinet with the Moorestown Community Band and has done volunteer performances for both seniors and preschool groups. But in order to make his dream job happen, he needs more help.

"He practices every day and is very good, but I don't have time or skills to come up with a marketing plan for him. He probably needs a demo CD. And if it worked, he would need more services to get to and from his gigs," said Luke's mother, Kathleen Whelan Ferris.

"He probably needs a manager, but the system does not really provide supports needed by a self-employed musician," she quipped.

According to his mother, Luke has autism and co-morbid mental health challenges. A 2012 high school graduate, Luke currently works part-time at Wawa. He got the job through experience gained during a 'Structured Learning Experience' when he was

## Luke Mammel, Musician



Luke Mammel, a 25-year-old musician on the autism spectrum, hopes to one day run a music program for preschoolers.

a student in the Standard 9 Transition Program at Y.A.L.E. School, a private school.

"He has a great boss, and because of his experiences at Standard 9, he is totally independent there," said Whelan Ferris.

By most accounts, Luke has a full life, and is engaged in his community. He plays basketball through the local JCC, has a weekly bowling date with friends, and has dinner with other friends about once a month. He also enjoys dinner with his father twice a week, and goes to the gym, where he swims and exercises.

Several days a week, he gets a ride to work through natural supports. For the other days, Luke's family hired someone through what is known as a 'self-hire.' The young man, who has been part of Luke's support system for more than two years, picks Luke up from work, they eat lunch, and then workout together at the gym.

"It has been great for him. For the first time I have total peace of mind," said Whelan Ferris.

“The work is exciting, and fun, and hard, all at the same time. It is a huge change in the system of supports provision, and it will take time,” she said.

Ford agrees. “DDD is on the right path. The system is new and there is a lot to learn, but good things can come from this,” she concluded.

“I think the service model simply has to be more mature in order for this to happen,” Witowsky said, who added that DDD is still “perfecting the model.”

“They are making changes to the system as they become aware of problems, but they don’t have all of the answers.” **P&F**

Whelan Ferris likes the person-centered planning process that helped bring these services and supports together for Luke.

“It was more informal than the IEP process and really concentrated on Luke’s hopes, dreams, and desires. It was very focused on him, and not limited to the resources that a school or provider might have. I have monthly contact with his support coordinator too,” she said.

Luke’s DDD budget allows for about 15 hours a week of paid support, some mileage, and memberships at the JCC and the local Y, but according to his mother, there are several days a week when Luke has no supports at all.

“I would like him to be more independent and active—to do more without me, but he is more dependent on me than ever. I know that is not the intent of this program,” she said.

Asked about natural supports, Whelan Ferris said it is not enough.

“I don’t know about the ‘natural supports’ everyone talks about because I don’t have that. There is no one else to lean on. The burden falls on me,” she said.

While she recognizes that her son’s dream of being a professional musician may take time and effort, she said her biggest worry is about his future.

“What will happen when I am not around to do all this for him. Who will support him then?”

## RESOURCES

The Arc of NJ Family Institute helps family members gain the tools necessary to become an effective advocate as well as supporting families as they try and navigate the service delivery systems.

<http://www.arcnj.org/programs/the-family-institute.html>

**732-828-2022**

The Collaborative is a new membership organization of individuals and organizations committed in purpose or in promise to the provision of conflict free individualized support coordination services. They seek to influence public policy; facilitate learning opportunities through personal and group training sessions, webinars, and conferences; and offer technical assistance in best practices in areas of person centered approaches, planning facilitation, and Medicaid compliance, including billing and finances.

[www.thecollaborativenj.org](http://www.thecollaborativenj.org)

The Boggs Center’s *Selecting a Support Coordination Agency: Making Choices, Becoming Empowered* guides for people with developmental disabilities and families provide information on what to consider when choosing an agency. The guides include questions to help people communicate what is important to them and suggestions for interviewing Support Coordination Agencies about basic information such as typical caseload and average turnover, knowledge and training, and experience working with individuals with developmental disabilities. These resources can be found on The Boggs Center’s website and ordered online at: <http://rwjms.rutgers.edu/boggscenter/products/SelectingandEvaluatingSupportCoordinationAgency.html> or by phone (732-235-9300). Spanish versions of the guides, *Selección de una agencia de coordinación de apoyo: Tomar decisiones, fortalecerse*, are also available.

The Division of Developmental Disabilities’ website has a page dedicated to support coordination, with helpful links, directories, and information.

[http://www.nj.gov/humanservices/ddd/services/support\\_coordination.html](http://www.nj.gov/humanservices/ddd/services/support_coordination.html)

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

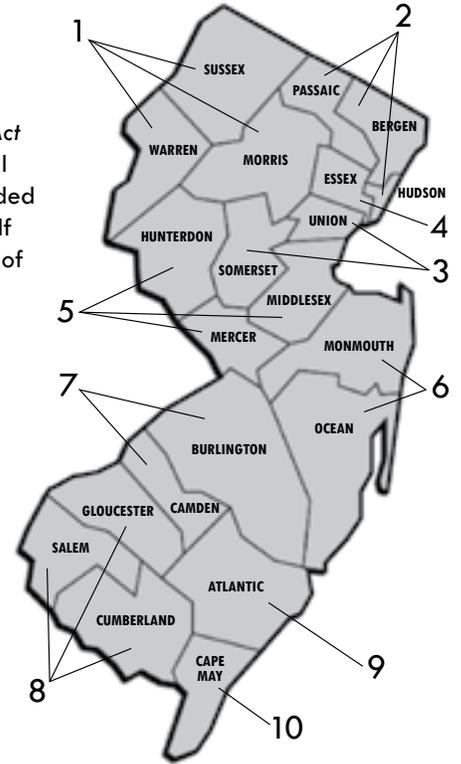
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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 living at home with their families. 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 or individuals 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](mailto:kyoko.coco@njcdd.org) Or visit our website at [www.njcdd.org](http://www.njcdd.org) and follow the link to Family Support.**

#### 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 a developmental disability.

The system of Family Support shall include, but not be limited to:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers

Visit the NJ Council on Developmental Disabilities' web site at: [www.njcdd.org](http://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**  
**PO Box 12**  
**Pompton Plains, NJ 07444**  
**e-mail: [rfspc1@gmail.com](mailto:rfspc1@gmail.com)**  
**Chair: Margaret Hefferle**

Meets the third Tuesday of each month  
at Morristown Memorial Hospital  
100 Madison Ave.  
Level B, Conference Rm. #2  
Morristown, NJ 07962  
7:00 p.m.—9:00 p.m.

## 2 BERGEN, HUDSON, PASSAIC

**RFSPC#2**  
**PO Box 443**  
**Jersey City, NJ 07302**  
**e-mail: [RFSPC2@gmail.com](mailto:RFSPC2@gmail.com)**  
**Co-Chairs: Frank Fiore, Fel Lim**

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

## 3 SOMERSET, UNION

**RFSPC#3**  
**PO Box 5997**  
**Hillsborough, NJ 08844**  
**e-mail: [rfspc3@gmail.com](mailto: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**  
**PO Box 1742**  
**Bloomfield, NJ 07003**  
**e-mail: [rfspc4@yahoo.com](mailto:rfspc4@yahoo.com)**  
**Co-Chairs: Rebekah Novemsky,  
Yolanda Smith**

Meets the first Wednesday of each month  
Bloomfield Civic Center Music Room  
84 North Broad St.  
Bloomfield, NJ 07003  
7:30 p.m.—9:30 p.m.

## 5 HUNTERDON, MIDDLESEX, MERCER

**RFSPC #5**  
**e-mail: [rfspc5nj@gmail.com](mailto:rfspc5nj@gmail.com)**  
**Co-Chairs: Paul Blaustein, Cheryl Crick**

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](mailto:rfspc6-chair@excite.com)**  
**Chair: Mike Brill**

Meets the second Thursday of each month  
Lakewood Municipal Bldg.  
231 Third St., 2nd floor  
Lakewood, NJ 08701  
7:30 p.m.—9:30 p.m.

## 7 BURLINGTON, CAMDEN

**RFSPC #7**  
**PO Box 641**  
**Mt. Laurel, NJ 08054**  
**e-mail: [rfspc7@gmail.com](mailto:rfspc7@gmail.com)**  
**Chair: Lisa O'Keefe**

Meets the fourth Tuesday of each month  
The Arc of Camden County  
215 West White Horse Pike  
Berlin, NJ 08009  
7:00 p.m.—9:00 p.m.

## 8 CUMBERLAND, SALEM, GLOUCESTER

**RFSPC #8**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC8@gmail.com](mailto:RFSPC8@gmail.com)**  
**Co-Chairs: Sandra Backensto,  
Lisa Parles**

Meeting dates posted at [njcdd.org](http://njcdd.org)  
River Winds Community Center  
1000 Riverwinds Dr.  
West Deptford, NJ 08086  
6:00 p.m.-7:30 p.m.

## 9 ATLANTIC

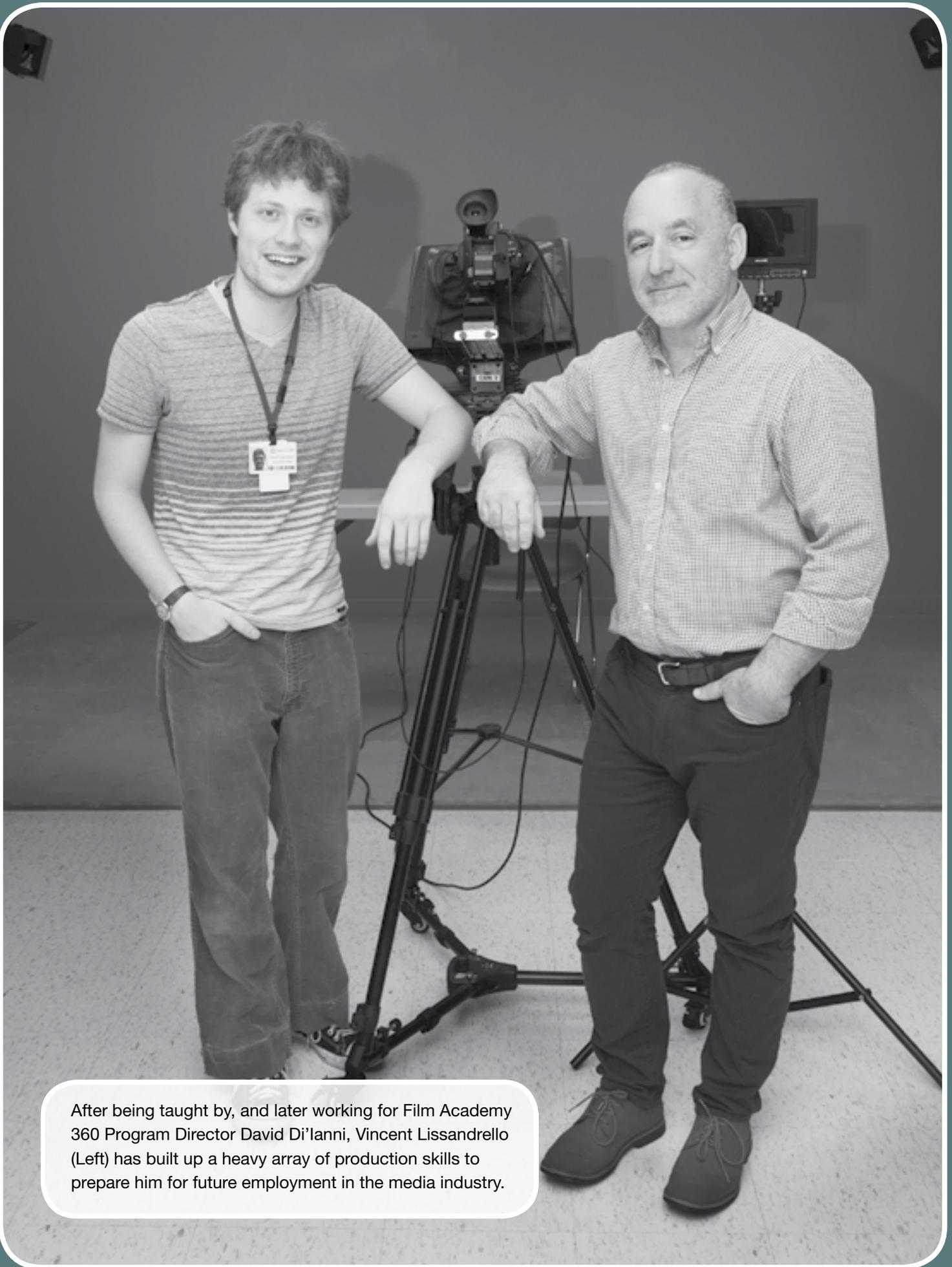
**RFSPC #9**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC9@yahoo.com](mailto:RFSPC9@yahoo.com)**  
**Co-Chairs: Lorry Farber,  
Mary Ann Philippi**

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

## 10 CAPE MAY

**RFSPC #10**  
**PO Box 199**  
**South Dennis, NJ 08245**  
**e-mail: [RFSPC10@yahoo.com](mailto:RFSPC10@yahoo.com)**  
**chair: Anne Borger**

Meets the third Thursday of the month  
except for July, August, December,  
and January  
Cape May Special Services School  
148 Crest Haven Dr.  
Cape May Court House, NJ 08223  
Meeting times TBD



After being taught by, and later working for Film Academy 360 Program Director David Di'Ianni, Vincent Lissandrello (Left) has built up a heavy array of production skills to prepare him for future employment in the media industry.

# Film Academy 360

## State-of-the-Art Media Production Training for Students on the Autism Spectrum

By Maryann B. Hunsberger

When Vincent Lissandrello graduated from Spectrum 360 Upper School in 2015, he already had several years of practical work experience under his belt. Now, the 22-year-old from Midland Park, NJ, is back to teach at the school that has given him the skills needed to succeed. The current Bergen Community College broadcasting major began working as an instructional assistant for Spectrum 360's state-of-the-art film program, Film Academy 360, five years ago while still a student there. The students he works with are all on the autism spectrum—as is Lissandrello.

Lissandrello also teaches after-school and Saturday classes at the film school, held on Spectrum 360's Upper School campus in Livingston, NJ. He helps teach everything from pre- to post-production as he helps students to shoot and edit movies.

This scenario is exactly what David Di'Ianni had in mind when he created Film Academy 360. While working as a TV producer and director in New York City and Europe, he saw media change drastically because of technology and the internet. "I saw kids making good quality videos with small digital cameras and posting them on YouTube for millions of people to see. I thought I could bring something similar to the table, education-wise."

When Di'Ianni returned to the US, he took a job as an instructional assistant at Spectrum 360. He learned that their CEO and executive director, Bruce Ettinger, shared his vision. "I had visited a program in California that teaches students with autism to do video editing and animation. I had heard about similar programs in Israel and thought it could be an area of strength for our students. David and I began talking and this evolved together. A lot of children on the spectrum are very visual, so this is suited to their strengths. It's amazing how well it has worked."

The daytime film course is for current Spectrum 360 Upper School students. The after-school and Saturday programs are mostly comprised of teens and young adults who attend other special education schools.

Film Academy 360 is an extension of Spectrum 360's mission of helping students with autism to find their unique strengths. Ettinger said, "Many children come through other districts that can't meet their needs. Many have met frustration and failure. We want to find the special strengths and abilities they have when they come to us. The students who come to us have had their lives impacted."

Ettinger said he has seen Lissandrello blossom from attending both the school and the film academy. "When Vincent came to us, he had a lot of anxiety, was very shy, and had trouble relating to people. He would hardly say a word. Now he teaches students and makes presentations at film festivals with such self-assurance. It's really helped his self-confidence and socialization skills."

Like Lissandrello, 15-year-old Ethan L. was struggling socially at school. His mother, Eileen Forman of Summit, NJ met Di'Ianni at an autism conference and thought Film Academy 360 would benefit her son. "Like a lot of kids, Ethan has

always been interested in videos and YouTube. This sounded like something at which he could do well,” Forman said. “Many kids on the autism spectrum have communication difficulties, so doing film gives them a longer time to think about what they want to say. They learn to express things in a controlled way. It’s very structured and socially appropriate,” she added.

Forman said the after-school and Saturday program is Ethan’s most successful socialization experience of each week. “He feels completely accepted there. He isn’t the most articulate kid, but he’s accepted for what he is doing. Because of his disability, he gets obsessive about topics other kids aren’t interested in. Here, he has a topic to talk about that all the kids are interested in. They are a good audience for each other. They work as a team. He talks about the other kids and about their videos, such as their current project making comedy videos.”

The skills the students learn go beyond socializing, however. Nine students this year have become certified in Adobe, the largest graphic arts software producer. The certification process

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Staffer Sarah Getsy going over the script for a news program with student Alex Wiseman.



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At Film Academy 360, students on the autism spectrum get training in digital media and graphic design.

allows potential employers to see that a prospective employee is proficient in their software.

Since Film Academy 360 is a functioning production company, the students edit professionally-shot films that have been submitted to festivals. One was submitted to the Tribeca Film Festival. “It allows the students to play Hollywood editor,” said Di’Ianni. “But, it’s a very high-skilled, high-functioning activity.”

When clients approach Film Academy 360, Di’Ianni hires the after-hours students to work on those projects to provide pre-career experience. This allows them to have an easier entry process into the working world. “These are the students who have advanced enough to be independently productive in the studio. We work for high-level organizations and do the presentation videos that they use in conferences and marketing. We have a good track record in terms of satisfied customers. We explain to companies that this work helps us give the students the tools to succeed, while guaranteeing a level of quality.”

Private organizations also assign video projects to do for a fee or donations. The students shot a golf outing to raise funds for autism awareness. They have made promotional and social-skills videos for bestselling author Jed Baker, whose videos show visual examples of how to handle difficult situations for people with autism. The



Vincent Lissandrelo (far left), a former student and current instructor at Film Academy 360, works with David Di'Ianni (far right) to assist students in creating original video productions.

students serve as both actors and producers in making them. They have also shot promotional videos for other private schools' websites.

The students also make films to submit to film festivals. Two years in a row, the students shared their films at the Morris Museum's theater. Some students presented films at the Montclair Film Festival and the Real Abilities Film Festival. Lissandrelo served as a boom operator at the Montclair Festival. Di'Ianni said, "Five of my students attended the JCC Film Festival, presented a film, and answered questions from the audience. As a teacher, to see them answering appropriately and being accepted is a really good feeling."

Two of Di'Ianni's students are employed part-time in the media field and three others have secured internships. He has students who are ready and able to work full-time.

Lissandrelo finds himself amazed at the work he does. "I never expected that I'd be doing something like this. I went from making home movies

with my friends to now having a job, making good money, and helping students with autism to make these films."

He has gone back and forth between whether he wants to work in film or teach film. He has come to the conclusion that he wants to work for a small production company in the city that makes TV commercials and TV shows. "My strongest skills are in taking video that has already been shot and working on the format. My true calling would be film editing. I've been working here for five years and my boss said he wants me to move on because I belong in a production company."

Ettinger points out that in the next five to seven years, hundreds of thousands of young adults with disabilities are going to need jobs. "We have to think out of the box to find them high value jobs. We have to think of their strengths and how we can create jobs based on those strengths. We also have a responsibility to enhance their self-esteem and give them work and jobs where they can succeed. Everyone needs that." **P&F**



## On Being a DSP

# The Challenges and Rewards of the Direct Support Profession

By Jonathan Jaffe

It is a bit hectic at 10 am on a weekday morning at the Point Breeze Adult Training Center in Frenchtown, NJ.

There are typically between 28 and 30 clients at this day program, which The Arc of Hunterdon County runs. Attendees have various forms of disabilities, from cerebral palsy to bi-polar disorder to autism and other intellectual and developmental disabilities. Some folks can move around on their own, others need walkers and wheelchairs.

There are eight Direct Support Professionals (DSPs) working the 8:30 am to 4 pm shift, making sure that all needs are met. No one stops moving as one activity is held after another. Clients range in age from 21 to 88. There are special diets, personal care and hygiene needs, and plenty of loud chatter.

In the middle of this bustle of activity stands Sue Kertesz, a DSP with The Arc for 24 years. It is an employer, she says, that has provided

terrific support over the years, one of the reasons for her long tenure.



Sue Kertesz has been a DSP for 25 years.

Kertesz runs a daily program in the kitchen, in which she works with clients to prepare meals and snacks. She also oversees lunch, making sure the right meals are sliced, diced, moist, and (when needed) pureed, as well as accommodating to an ever-changing list of dietary restrictions.

Kertesz is moving, moving, moving on any given day. Eating a quick lunch in between the steady bathroom needs of clients. Cleaning up the kitchen again and again. Making sure medication is taken and in the right doses.

For all this work, and much, much more, she earns

\$13.45 an hour—an increase of only \$6 an hour since the first day she became a DSP in 1992.

“I love these guys and I love everyone here,” she said. “But if my husband was not working, there is no way I could afford to stay here.”

Low pay is a steady bone of contention among DSPs; they are constantly reminded that they are paid among the lowest in the health care profession. They have the daily chores of physically lifting grown men and women, administering a range of medications to those in a variety of medical situations including hospice, and continually receiving training in first aid and CPR to a fragile population.

For many, DSPs are the only companions a client may have, as some do not have family or friends. DSPs tuck in clients at night, and bring them to the bathroom at sunrise. They celebrate

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Sue Kertesz, a DSP at The Arc of Hunterdon County, teaches a cooking class at a day program for adults with developmental disabilities



birthdays and special events. And they are often there to coordinate hospice care and, ultimately, mourn the passing of someone they care for.

Kertesz is quick to admit she has a challenging profession. Any of the DSPs who work at Point Breeze or anywhere else in the state could likely secure a higher-paying job working in retail or in an office.

But it takes a special person to become a DSP. And the need continues to grow.

“Home Health Care” and “Personal Care Aides” are considered the third and fourth fastest-growing occupations in the country between 2012 and 2018. In 2012, New Jersey had about 41,170 home health aides or personal care aides. Researchers project increases of 43 percent and 26 percent, respectively, in the next four years.

It is not just a state issue. The United States will require approximately 1.2 million full-time DSPs to meet the needs of roughly 1.4 million people with intellectual or developmental disabilities for residential, vocational, or other supports by 2020.

People with developmental disabilities are living longer than ever, requiring in-home support that addresses both the disability, as well as the regular aging of the body. The limited pool of dedicated and qualified DSPs in the state are continually facing new challenges and demands.

It is a national issue; and this is not a new issue,” said Joseph Macbeth, executive director of the National Alliance for Direct Support Professionals, based in Albany, NY. “The overall economy is improving. There are better-paying jobs, and many DSPs are leaving their jobs for better-paying ones. It happens with every economic recovery and this is no exception.”

“For this type of work, you need to be compassionate, passionate, and recognize you are fully responsible for the care of other people,” said Rachel Harget, a manager at The Arc of Camden County and a DSP for six years. “You have to take them to all their appointments and make sure their living space is safe and clean. So much goes into being a DSP.”

Harget said she received plenty of inquiries from people interested in becoming DSPs. But

*“Home Health Care” and “Personal Care Aides” are considered the third and fourth fastest-growing occupations in the country between 2012 and 2018.*

once they get involved, go through the training, and experience all that is involved, it is difficult for them to remain. Because of the low pay, many DSPs need a second job. She notes the average pay varies somewhere between \$9.50 an hour and \$12.75 an hour.

The US is the largest purchaser of DSP support. In fact, Medicaid and Medicare programs finance more than 80 percent of the total cost. One reason DSP wages are so low is because that’s the amount the feds are willing to reimburse states for providing the service through state programs.

“The biggest challenge is that any of our DSPs can go into Walmart or Kmart and get a higher-paying job,” Harget said. “When you work as a DSP, you don’t sit down. You are showing people how to integrate into the community, teaching them to bank, to order at a restaurant, to grocery shop, to do laundry. You are working, always, to make someone more independent.”

Harget oversees nine DSPs in Lindenwold. As group homes require 24-hour supervision, the DSPs have hours around-the-clock. At Harget’s home, the shifts are 7:30 am to 3:30 pm, 3:30 pm to 11 pm, and 11 pm to 8 am. “The work hours are very difficult,” she admitted, noting the DSPs with whom she works are caring for eight men and four women, two to each apartment. “There is a lot of time away from home.”

It often takes a selfless breed to be a DSP. Jessica Carolan of Jefferson, NJ is the perfect example. After her 40-hour workweek at Alexander House in Jefferson, she cares for her own family, including daughters who are ages 10 and 4.



DSPs not only see to clients’ physical and medical needs, but also offer companionship and enrich the lives of the individuals they serve.

“You don’t really know what you are getting into until you start work,” said Carolan, who was a stay-at-home mom who became a DSP three years ago. “These guys become your family really quickly and you care about them. I enjoy taking care of them. I enjoy celebrating their birthdays and taking them on outings.”

Carolan, who works in a house that cares for a total of eight men and women with intellectual and development disabilities, said there are many challenges to her work. Besides the low pay, she works on major holidays and there are enormous responsibilities, such as dealing with catheters, colostomy bags, and detailed medications.

“You really need to draw the line; you can’t take your work home with you,” she said. “But you are also spending so much time with your



DSP Kaitlyn McDonald works with Scott Sawyer and Patty Whelan at The Arc of Hunterdon County, helping them to build life and socialization skills.

clients; they really become family and you can't help but care about them. You show them how to brush their teeth, you tuck them in at night, and you make sure they are ok.

"You do everything you can for them, and it is heartbreaking when they get sick," Carolan said. "You help them through hospice, maybe even bringing a donut as a special treat. Sometimes, they die. We had three women die in the past two years. It feels like losing a member of your family. You become that close. And you grieve from the loss."

To help make the job easier, and to stay connected with her family, Carolan said her husband, Doug, volunteers at Alexander House and her daughters are frequent visitors.

"Everyone's eyes light up when they see my girls," she said. "My daughters paint their nails and everyone laughs and has fun. It really makes this job feel special."

Clara Beck, who is Carolan's supervisor at Alexander House, has been working there for 22 years. Beck began as a part-time DSP, helping out on the weekends when her children were little.

For Beck, there has been a strong and clear

career track at Alexander House. She accepted a full-time position, ultimately moving from program assistant to associate director to her present position, as director, beginning in 2006. She now oversees eight staff members.

"If you want to have a career as a DSP, you need to take every available training," she said. "Learn everything you can, watch people you work with, and ask a lot of questions."

"But if you are in it for the money, you are in it for the wrong reason."

Beck said the right DSP has to be someone who is always curious and eager to take the initiative. That person is someone who is always looking for ways to make life better for the residents, such as researching the Internet for suggestions on new ways to tackle old issues.

"When people come in for an interview, I am brutally honest," Beck said. "If you are easily intimidated, this is not the right job for you. This is not a 9-5 job, and you won't do the same thing every day. It is a challenge.

"But if you are up for that challenge, this is an amazing job." **P&F**

# The Forgotten Minority

By Marianne Valls

Coming home from shopping one day, I tried to board a bus with my walker. The driver denied me access, saying only people who used wheel chairs could use the lift. Seeing the driver's supervisor also on-board, I felt certain that he would be corrected. But to no avail. The supervisor agreed with the driver. Being on the New NJ TRANSIT ADA Taskforce, I knew they were wrong.

It was definitely a case of discrimination. Yet I could sense that day that my fellow passengers did not think that a woman with a walker trying to board a bus would fall into the category of a discriminated minority. After all, I was no Rosa Parks.

According to one online dictionary, "A minority is a racial, ethnic, religious, or social subdivision of a society that is subordinate to the dominant group in political, financial, or social power without regard to the size of these groups". However, few people think of people with disabilities as being a minority.

According to the University of New Hampshire's Institute on Disability, "If people with disabilities were a formally recognized minority group, at 19% of the population, they would be the largest minority group in the United States." Like any other minority group, many people with disabilities live in poverty, are unemployed, lack adequate housing, and are in poor health. Yet despite the statistics, people with disabilities are still known as the "Orphan Minority".



In a magnificent speech given at the eight annual Jacobus tenBroek Disability Law Symposium entitled *People with Disabilities: The Orphan Minority*, blind disability advocacy pioneer Dr. Fredric K. Schroeder demonstrates why many people who have limitations—be they physical or intellectual—are not seen by the mainstream (or for that matter, themselves) as a minority.

In my experience, people with disabilities experience all the prejudice and discrimination as other minority groups. However, society does not recognize the discrimination faced by people with limitations as equal to other minorities. Strangely, society believes that the obstacles experienced by people with disabilities within their communities are a consequence of their "infirmity". Therefore, they are not considered part of the Civil Rights Movement.

There are intense differences between *The Americans with Disabilities Act* and other civil

rights laws. Other laws designed to eliminate segregation and discrimination give minorities rights, but nowhere in Title VII of *The Civil Rights Act of 1964* does the word “qualified” appear as it does in the ADA. The Act merely says, “It shall be an unlawful practice for an employer. . . . to discriminate against any individual with respect to his compensation, conditions, or privileges of employment, because of such individual’s race, color, religion, sex, or national origin.”—*Title VII, Civil Rights Act 1964 Sec. 703(a)(1) or 42 USC 2000e—2(a)(1)*.

Dr. Schroeder argues that the section of *The Americans with Disabilities Act* that impacts employment discrimination is “a limited prohibition.” There is no limitation language used in other civil rights law. Only the ADA requires employers to hire only those individuals with disabilities who are deemed “qualified.” The ADA further states that the person with a disability must perform “the essential functions of a job with or without a reasonable accommodation.” Yet, the employer decides what the “essential” functions of the employment position are.

Framing the ADA differently from other civil rights laws puts people who have impairments at a disadvantage. Hence, many of us will forever live in poverty.

The most logical way out of poverty is a paycheck. Receiving a salary that competes with the average worker puts everyone on an equal playing field. If people with disabilities are to achieve to true equality, changes to certain laws should be made. For example, *The Fair Labor Standards Act*, Section 14c must be repealed. Under this section of the law, an exception is granted from minimum wage requirements, allowing employers to pay sub-minimum wages to certain workers with disabilities. According to Dr. Schroeder, not only does this section of the law cause “economic harm” to people with impairments, but laws like this also isolate people with disabilities from the rest of the community. They help feed into the public’s perception of individuals with physical and/or intellectual challenges as inferior.

Overall, the mainstream views people who are affected by these laws as belonging to a different class. Society has always treated this segment of the population as a people needing care and protection from the rest of the world. They are viewed as “less productive” than their able-bodied peers. Out of a false sense of benevolence, people with disabilities are kept from competition, and thus insulated from the rest of the community.

By law, Social Security limits my, and everyone else who receives benefits, productivity. I can only earn so much before my Supplement Social Security income is terminated. With the loss of benefits, medical coverage is also lost. The disability laws of Social Security are based on welfare laws, which state that once an individual achieves gainful employment, his or her benefits stop. However, as many readers with disabilities know, the needs of individuals are vastly different, regardless of whether they can find work that enables them to successfully leave the welfare rolls. The cost of adapted equipment, personal care staff, and/or medical maintenance can be overwhelming for any human being facing unusual obstacles.

I share with you my meeting with a man who had quadriplegia to illustrate my point. At the time I met him, he was doing volunteer work. He told me he once was employed as a director of a Center of Independent Living, but was forced to quit because he was unable to pay for a personal assistant. Not only was he forced to give up his job, but the nation lost a tax payer.

This past year has given me hope that people with disabilities will gain the minority status they truly deserve. There is a growing awareness of our presence in the media with shows such as ABC’s *Speechless* and A&E’s *Born This Way*. We also saw more people with impairments given a national spotlight during this year’s election.

*The Americans with Disabilities Act* (ADA) opened many doorways for a class of people who never participated fully in society before its passage. However, the ADA only pushed the door open slightly. There is much more to be done. **P&F**



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Laura Bracey and Brett Pollock at HollyDELL day program  
Photo by Rebecca Shavulsky