

People & Families

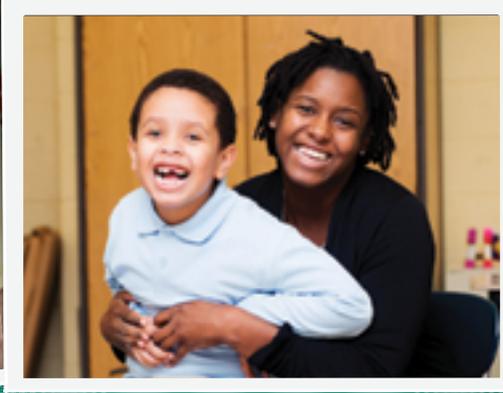
NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

WINTER 2019



Matthew Valentine, PA-C

Matt Valentine **Practicing Medicine
with a Disability**



NEW JERSEY
REGIONAL 
FAMILY SUPPORT
PLANNING COUNCILS

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Contact

Kyoko Coco | 609-341-3112 | kyoko.coco@njcdd.org

Rebekah Novemsky | 609-984-4510 | rebekah.novemsky@njcdd.org

 www.facebook.com/NJFSPC





PUBLISHER New Jersey Council on Developmental Disabilities

CHAIRPERSON Paul A. Blaustein

EXECUTIVE DIRECTOR Mercedes Witowsky

EDITOR Gary L. Brown

EDITORIAL BOARD MEMBERS

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Carole Tonks, Alliance Center for Independence

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SELF ADVOCATE MEMBERS

Todd Emmons, Andrew McGeady,
Myrta Rosa, Gary Rubin, Kevin Nuñez

**PARENT, FAMILY MEMBER,
AND GUARDIAN MEMBERS**

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Helen Steinberg, Kara Sellix

PUBLIC MEMBER

William Testa, The Arc/Morris Chapter

FEDERALLY MANDATED MEMBERS

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Phyllis Melendez, Division of Medical Assistance
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TBD, Division of Vocational Rehabilitation Services
Felecia Walton, Division of Family Health Services
Joyce Jelley, The Boggs Center on
Developmental Disabilities at Rutgers University
Gwen Orłowski, Esq., Disability Rights NJ

The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

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New Jersey Council on Developmental Disabilities, PO Box 700, Trenton, NJ 08625-0700. TELEPHONE: 609.292.3745 TDD 609.777.3238 FAX 609.292.7114 E-MAIL njcdd@njcdd.org INTERNET www.njcdd.org

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Matt Valentine
Photo by Rebecca Shavulsky

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COVER STORY

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Practicing Medicine with a Disability

Matt Valentine became interested in medicine as a child. Through hard work and perseverance, Valentine began working as an EMT and ambulance driver. During August, 2018, he graduated from Philadelphia College of Osteopathic Medicine with a master’s degree in health sciences/physician assistant studies. Since graduating, he has been working as an emergency medicine physician assistant.

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28 SUPPORTED DECISION-MAKING Enhancing Quality of Life

Disability advocates are now asking for a viable alternative to legal guardianship, in which people with intellectual and/or developmental disabilities (I/DD) can have more of a say in how they live. A new movement called “supported decision-making,” is gaining a foothold across the United States. It gives people with I/DD much better opportunity to self-direct.

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The transition to the fee-for-service system has been challenging for many individuals, families and guardians. This new segment replaces several myths with factual information.



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Eileen Hurley & Gabrielle Bohon

The Statewide Family Support Planning Council brings together parents and family members of people with developmental disabilities, who exchange knowledge and information about services. As members advocate for families and individuals with developmental disabilities at the local level, their work is overseen and coordinated through two new leaders of the statewide council: Eileen Hurley and Gabrielle Bohon.

from the Chairperson ■

Supporting DSP Wage Increases



Self-advocates, families and providers agree that the direct service professional (DSP) crisis is the foremost challenge to the DD services system. For 10 years, from 2007 through 2017, the state did not increase the rates it paid for services provided by licensed providers or

families who self-direct the services their family members receive.

No funding was provided for increases in staff salaries, or to cover the cost increases for goods and services purchased by providers. DSPs are the indispensable element of the DD services system. DSPs provide intimate personal care services, bathe, toilet, feed, transport, administer medication, provide companionship, and assess personal needs. They are responsible for the health, safety, well-being, happiness and fulfillment of the highly vulnerable individuals whom they serve. The DSP performs a complicated, demanding, critical role, which is both physically and emotionally taxing.

Clearly, this is not an entry level, unskilled job. DSPs who work in state-operated developmental centers, received an average salary of \$40,350 in 2015 and have received subsequent wage increases. In contrast, DSPs working for licensed providers currently receive only \$24,250. This is not a “living wage,” and condemns DSPs to membership in the working poor.

DSPs employed directly by the state also receive a generous pension and the “gold plated” state employee healthcare coverage. Social justice would require DSPs employed by state contractors or by providers reimbursed by Medicaid, who perform the same work as DSPs in state DCs, to receive the same salaries as state employees. The state’s Fiscal Year 2019 Budget included a wage increase for DSPs of \$0.40-45 per hour, with no increase to cover other cost increases experienced by providers.

This is the first increase in compensation paid by the state since 2007. It is only one small step. DSPs

must be paid commensurately with their required skills, the tasks they perform and the essential bond that forms with those whom they serve. We applaud the Governor’s and the Legislature’s agreement to increase New Jersey’s minimum wage to \$15 over several years, but it is the state’s responsibility to provide the funds to raise DSPs to at least the prospective new minimum wage.

The result of a decade of inadequate funding for the DD services system is the current crisis, which we fear will lead to disaster. Inadequate wages have led to rising vacancies and turnover. Vacant positions exceed 20 percent and annual turnover is approaching 45 percent statewide. The human costs of this situation are widespread and devastating.

Vulnerable individuals experience cancelled medical appointments, due to the lack of a DSP to bring them to a physician. They are unable to participate in the community activities that make all our lives worthwhile due to the lack of DSPs to accompany them. Instead our loved ones sit in their group homes or apartments, despite Home and Community Based Service (HCBS) requirements for community inclusion, which is a slogan, not a regular part of their lives. They must wait for basic services, such as bathing, toileting, dressing, eating and medicines. The lack of DSPs and the lack of a stable DSP workforce, familiar with the needs of our loved ones, is causing a marked deterioration in their health and the quality of their lives.

This trend of inadequate funding is not sustainable. The FY2020 State Budget will either start the process of providing our loved ones with the quality of health and life they deserve, or it will continue the current march toward disaster. Here in New Jersey, we are committed to caring for the most vulnerable among us. I implore Governor Murphy and the Legislature to act for our loved ones and for the dedicated staff who care for them each and every day.

*Paul A. Blaustein
Chairperson*

New Jersey Council on Developmental Disabilities

NJCDD Position Statement on The Rights of Individuals with Developmental Disabilities

The New Jersey Council on Developmental Disabilities endorses the following statement supporting the rights of individuals with intellectual and/or developmental disabilities (I/DD):

Position

People with intellectual and/or developmental disabilities have the same basic legal, civil and human rights as other citizens.¹

Disability is a natural part of the human experience that does not diminish the right of individuals with intellectual and/or developmental disabilities to live independently, to exercise control and choice over their own lives, and to fully participate in and contribute to their communities through full inclusion in the economic, political, social, cultural, and educational mainstream of our society.

Background Information

Federal civil rights laws are clear in mandating the rights of individuals with I/DD:

“The ADA (Americans with Disabilities Act) prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits

one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.²”

The United Nations Convention on the Rights of Persons with Disabilities affirms:

“...the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination.³”

The rights of individuals with developmental disabilities described herein shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.

Government must continue to recognize and guarantee the civil and human rights of individuals with intellectual and developmental disabilities. This includes advancing laws and regulations that provide individuals with the information, skills, opportunities, and supports to pursue meaningful, fulfilling and productive lives and to live free of abuse, neglect, financial and sexual exploitation.

Adopted: October 25, 2018

¹ The Arc, 2018

² “A Guide to Disability Rights Laws,” US Department of Justice, 2018

³ <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

One-Stop System to Give NJ Seniors, Disabled Access to Medical, Other Programs

By: Lilo H. Stainton

From: NJSpotlight.com—November 20, 2018

There's now a single online entryway through which New Jersey seniors and disabled residents can sign up for public programs in one go. It's called NJSave.

Low-income seniors and disabled residents in New Jersey now have a single online entryway to multiple public programs that can help them pay for health insurance, pharmaceuticals and other critical living expenses, including food and home heating.

The state Department of Human Services launched the NJSave electronic application system earlier this month, enabling qualified tech-savvy citizens to access various savings and assistance programs in one sitting. In the past, each program required its own paper application and eligibility assessment.

"This application gives older New Jerseyans, individuals with disabilities, and their caregivers a new, easily-accessible way to get the help they need to maintain their health and financial well-being," said Louise Rush, director of the DHS Division of Aging. Individuals can still enroll on paper and get help by phone.

"This application gives older New Jerseyans, individuals with disabilities, and their caregivers a new, easily-accessible way to get the help they need to maintain their health and financial well-being."

Louise Rush,
director of the DHS Division of Aging

The shift is one of a number of changes state agencies have recently made to modernize and upgrade the systems they use to enroll and interact with program participants, advocates and the public in general.

Earlier this year, the Office of the Attorney General unveiled NJCares.gov, with statistics on drug use and its impacts. And last week the state

Department of Health launched a complementary Opioid Data Dashboard, a searchable tool that includes treatment and hospitalization figures.

System for Medicaid Needs More Work

The DHS also rolled out a Medicaid Data Dashboard in September, a website that features enrollment statistics, highlights trends dating back to 2014, and links to separate application sites. And NJHelps.org was launched in 2017 to serve as a single

point of entry for Medicaid, cash assistance and food stamp programs, although each still requires a separate application.

But still in progress is a single, integrated electronic application system that can automatically connect low-income residents to Medicaid

and other income-eligible programs—something that’s been on the state’s to-do list for more than a decade and remains a priority for policy experts and some lawmakers.

“The system that is in place now is a patchwork of county, state and federal social services with electronic processes that vary in their timing and accuracy rates,” said Sen. Joe Vitale (D-Middlesex), who has led efforts to reform the Medicaid eligibility mechanisms; a bill prompting the DHS to do so passed the Senate in late October but awaits a hearing in the Assembly. “It is inefficient for state and the applicants applying for health coverage,” he said.

DHS officials said efforts are ongoing to modernize the electronic eligibility system for Medicaid, which now covers 1.8 million residents, but there is no timeline or budget for the work. Initial efforts to do so date to 2007 and involve a failed tech contract that cost the state \$10 million; the federal government lost more \$56 million on the deal.

NJSave, the new senior-services portal, is designed to serve hundreds of thousands of beneficiaries, family members and other caregivers who assist them. Visitors can access help to cover drug costs and apply for programs that provide funding for hearing aids, fall-detection devices and Medicare premiums. They can also connect with heating and energy assistance, food stamps and other public support, assuming they meet certain criteria.

Important to Streamline The Process

“It’s important that seniors across New Jersey are able to access the services and supports for which they’re eligible,” said Stephanie Hunsinger, state director for AARP New Jersey. “Any step that consolidates and simplifies the application process

for those services is a step in the right direction, particularly for the 1.1 million family caregivers in our state.”

NJSave programs are open to individuals who are at least 65 years old or receiving Social Security disability payments and live in New Jersey; caregivers can help them to apply. Some programs have income restrictions. The system allows users to fill out applications and create

accounts that help them monitor their access; the state also created a video tutorial to help people navigate the process.

“NJSave will help older New Jerseyans and their families with a simpler way to check out the programs and services available to them,” said DHS commissioner Carole Johnson. “We are delighted to provide this new tool to help connect individuals to benefits and services.”

Users can access the following programs through the new website:

- Pharmaceutical Assistance to the Aged and Disabled (PAAD)
- Hearing Aid Assistance to the Aged and Disabled (HAAAD)
- Lifeline Utility Assistance
- Medicare Savings Programs
- Medicare Part D’s Low Income Subsidy (LIS, also known as “Extra Help”)
- Senior Gold Prescription Discount Program

The new site can also screen users for the following services:

- Universal Service Fund (USF)
- Low-Income Heating and Energy Assistance Program (LIHEAP)
- Supplemental Nutrition Assistance Program (SNAP)



FDA To Finalize Ban On Shock Devices Used On Those With Special Needs

By: Michelle Diamant

From: DisabilityScoop.com—December 17, 2018

Two years after proposing a ban on devices used to administer electric shocks on people with developmental disabilities, federal regulators say they intend to move forward with the plan.

The Food and Drug Administration will finalize a 2016 proposal to bar so-called electrical stimulation devices, according to Scott Gottlieb, the agency’s commissioner.

“We believe these products present an unreasonable and substantial risk to public health that cannot be corrected or eliminated through changes to the labeling,” Gottlieb wrote.

The devices use electrodes attached to the skin to deliver electric shocks in order to condition individuals not to engage in self-injurious or aggressive behaviors.

The Judge Rotenberg Educational Center in Canton, Mass., which serves children and adults with developmental disabilities as well as those with behavioral and emotional problems, is the only facility in the country where the electrical stimulation devices are known to be used.

In a 2014 FDA report, investigators said that former students reported burns, scars, muscle spasms, seizures and other issues from the skin shocks and said the experience left them “fearful” and “anxious.” The agency subsequently proposed a ban, but has failed to act further.

Now, with a notice in its fall agenda, the FDA is formally signaling its intention to issue final regulations by the end of 2019.

The move comes after activists with the disability rights group ADAPT camped out in front

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- Stay informed on important developmental disability news from around our state
- Learn more about the NJCDD's programs for self-advocates and families, as well as new ways to participate

of Gottlieb's condominium in Washington, D.C. for 12 days earlier this year in an effort to pressure his agency to finalize the regulations.

The Rotenberg Center's supporters say that electric shocks are a needed option for individuals with severe behavior issues who have not responded to other approaches. In a statement, the center said that it will fight any efforts to ban the electric shock devices, noting a recent court decision in their favor.

"The Judge Rotenberg Educational Center (JRC) and the families whose children receive or have received this life saving treatment will continue to advocate and will move to litigate if that becomes necessary to preserve this court approved treatment," the statement said. "As you are aware, JRC prevailed in the recent

Massachusetts court trial where the court found that the treatment is humane, safe and highly effective for a population of clients who have exhausted all other options available to them and is only used as a treatment of last resort."

FDA spokeswoman Sandy Walsh said the rule is still being finalized and the agency "cannot speculate on specific timing."

For their part, ADAPT said it is pleased to see that federal regulators plan to move forward, but will keep up the pressure until a ban is in place.

"We must continue to press the FDA to move forward as quickly as possible with this ban because—everyday—disabled people are being tortured in the name of 'treatment,'" the group said in a statement.

Helping the Helpers: Advocates Want Task Force for Unpaid Caregivers

By: Lilo H. Stainton

From: NJSpotlight.com—December 19, 2018

What's needed to support family members and others who care for elderly or disabled loved ones?

As nearly one in five New Jerseyans knows well, helping elderly or disabled loved ones with their daily lives—running errands, sorting mail, dressing and feeding, or monitoring complex medical equipment—can take a serious emotional and physical toll over time.

Now, pending the say-so of the governor, Trenton is about to explore what more it can do to help such caregivers.

The New Jersey Assembly unanimously approved legislation on Monday that would create a task force to evaluate how state government supports unpaid caregivers, learn what else

is needed, and recommend policy and program changes in a report to the governor within a year.

The measure—first proposed and passed by lawmakers in 2014, but not signed by Republican former Gov. Chris Christie—cleared the state Senate without opposition in October and now awaits action from Gov. Phil Murphy, a Democrat. (Murphy's office has a policy of not commenting on pending legislation.)

Sponsored by a trio of Democratic Assembly members—Pamela Lampitt, Gabriela Mosquera and Valerie Vainieri Huttel—the measure (S-959) is designed to ensure that state agencies are properly supporting the wide range of caregivers—including family members, friends, neighbors and others in the community—who work informally

and for no pay to assist individuals at home or in other nonmedical facilities.

“Caregivers face an untold number of challenges in today’s society,” said Lampitt (D-Camden). “Many family caregivers are fulfilling these duties out of a sense of love and devotion, which can often make them feel anxious and overwhelmed. We want to make sure we are doing all we can to provide them with the resources and support they need to fill this critical role.”

A growing army of unpaid caregivers

According to the sponsors, an estimated 1.75 million Garden State residents are serving in this caregiver role. Their duties can range from cooking and cleaning to monitoring prescriptions and helping the individual walk or move about. Some, with limited or no formal training, also provide wound care, change colostomy bags, operate oxygen concentrators and use other medical equipment. The assistance they provide helps individuals remain more independent and can keep them out of more costly institutional care, the sponsors said.

“Family caregivers are the backbone of our long-term care system,” said Crystal McDonald, associate advocacy director for AARP New Jersey, which has been working to support the bill over the years. “It’s critical that our state has the services and systems in place to support the army of family caregivers who will become even more vital to our health care system as a whole,” she said.

The need for these caregivers has grown in recent years as Medicaid rules have changed, enabling more individuals to access care at home. That need is expected to expand even more as the massive baby boom generation ages and needs additional help. According to federal data, 15.8 percent of the state’s population is over age 65 —about 1.3 million people—and this group is expected to double by 2050. And the number of adults who need daily help is projected to grow twofold by 2020, the bill notes.

Currently, the services caregivers provide in New Jersey have an annual value of more than

\$13 billion, according to AARP. Most caregivers are in their 40s and 50s and the work, which can quickly become like a part-time job or more, can cost them more than \$600,000 in lost wages and missed Social Security benefits over a lifetime, the legislation notes. Previous unsuccessful campaigns to offset this burden have also called for a state tax credit of up to \$675 annually for those providing this service.

“Anyone who’s ever found themselves in a caregiver role understands the toll it can take,” said Mosquera (D-Camden). “Lack of sleep, privacy and the time to fulfill one’s own needs can increase the risk for depression and anxiety.”

Advocates: NJ Needs to Do More

Caring for individuals with dementia or other cognitive or behavioral issues can be particularly taxing, the bill notes. Vainieri Huttel (D-Bergen) said the task force must take an “honest look” at how it can better help those struggling with these challenges.

“Studies show that the emotional and physical health of caregivers often suffers as a result of the stress and physical demands they encounter, particularly when it comes to caring for people with dementia or Alzheimer’s,” she said.

New Jersey ranked 16th nationwide in 2017 in terms of support for family caregivers—up from 22nd in 2014—according to an annual scorecard published by national AARP groups, the Commonwealth Fund and a California-based organization focused on aging.

The scorecard report, which contained limited detail, found that the Garden State does well in some ways to support working caregivers. But it raised concern about transportation policies and limited use of models that involve person- or family-centered care, which is designed to better integrate caregivers in the process.

At present, there is no central “caregiver” agency in state government, but programs do exist to help relieve caregivers of certain responsibilities, if only in the short term. The Department

of Human Services oversees programs for the elderly and disabled residents and offers, or coordinates, some support services to benefit those in support roles. Its Division of Disability Services helps individuals connect with technology, transportation and other services. And the DHS's Division of Aging can link those in need with respite care and other programs offered by county agencies.

A Survey of Existing Services

To address the concerns raised by advocates and caregivers, the legislation—sponsored by Sen. Joe Vitale (D-Middlesex) and Linda Greenstein (D-Mercer) in the upper house—requires the state to set up an 11-member task force to review the current array of state services to support caregivers, and to survey and gather testimony from those doing this work. It would then have 12 months to compile and

submit to the governor a report with its findings and recommendations for policy changes.

The panel, which is set to dissolve a month after the report is submitted, would have limited support from the Department of Human Services and its members would be unpaid.

It would include the DHS commissioner or her designee, the AARP director, the head of the Home Care and Hospice Association of New Jersey, and representatives from leading organizations involved with Alzheimer's and mental illness, as well as from groups providing services for individuals with disabilities, and other related conditions. The governor would appoint three public members, including one who is a caregiver.

"I hope this task force will take to heart the real-life experiences of caregivers so we can create a greater support network statewide," Mosquera said.

Disability in Focus

The New Jersey Council on Developmental Disabilities

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Trump Administration Rescinds Guidance Amid Objections From Disability Advocates

By: Michelle Diament

From: DisabilityScoop.com—January 7, 2019

Guidance issued during the Obama administration, which was aimed at ensuring that minorities and students with disabilities weren't unfairly disciplined, is no more.

The U.S. Department of Justice and the Department of Education indicated in late December that a 2014 "Dear Colleague" letter informing schools of their responsibilities when meting out discipline has officially been rescinded.

The move came just days after a federal school safety panel chaired by Secretary of Education Betsy DeVos recommended abandoning the guidance.

The Justice Department said that the "Dear Colleague" letter was one of 69 guidance documents being revoked because they were deemed "unnecessary, outdated, inconsistent with existing law, or otherwise improper." The agency said the decision was in line with a 2017 executive order from President Donald Trump calling for federal entities to identify regulations for "repeal, replacement or modification."

DeVos was more specific, however, citing concerns that the guidance put too much emphasis on statistics.

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“Every student has the right to attend school free from fear of discrimination,” DeVos said. “In too many instances, though, I’ve heard from teachers and advocates that the previous administration’s discipline guidance often led to school environments where discipline decisions were based on a student’s race and where quotas became more important than the safety of students and teachers.”

Rescinding the guidance “makes it clear that discipline is a matter on which classroom teachers and local school leaders deserve and need autonomy,” DeVos said.

The “Dear Colleague” letter detailed how educators should prevent discipline from being administered in a way that disproportionately impacts certain children. Specifically, the document said that federal law prohibits “discriminatory discipline” based on race, disability and other factors.

In issuing the guidance, the Obama administration noted that just 12 percent of students across the country were enrolled in special education, but they represented about 20 percent of suspensions and expulsions and nearly a quarter of school-related arrests.

Disability advocates denounced the move to abandon the guidance.

“With the rescission of the discipline guidance, Secretary DeVos has communicated to our nation’s children with disabilities and children of color that they are not valuable and that the negative, disparate experiences they face at school do not matter,” said Denise Marshall, executive director of the Council of Parent Attorneys and Advocates. “Unfortunately, the rescission is likely to foster the growth of racially discriminatory practices where implicit bias and other negative factors disproportionately impact students with disabilities and students of color, including the use of abusive practices such as seclusion and restraint.”

Nonetheless, advocates stressed that while the guidance helped schools understand their responsibilities to students, revoking it does not do anything to change the underlying law.

In addition to the “Dear Colleague” letter on school discipline, the Trump administration also said it would rescind a handful of supporting documents that were issued at the same time. **P&F**

UPCOMING EVENTS

FAMILY SUPPORT PLANNING COUNCIL STATEWIDE MEETING

Saturday, March 23, 2019
9:30 a.m. – 3:00 p.m.

Hilton Garden Inn Hamilton
800 Route 130
Hamilton, NJ 08690

NJCDD COUNCIL MEETING

Thursday, March 28, 2019
9:30 a.m. – 2:00 p.m.

Hilton Garden Inn Hamilton
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Hamilton, NJ 08690

All Council meetings are open to the public—
If accommodations are required, please
contact the NJCDD offices at 609-292-3745
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Challenging Expectations

Parents With a Mission

By Brenda Considine

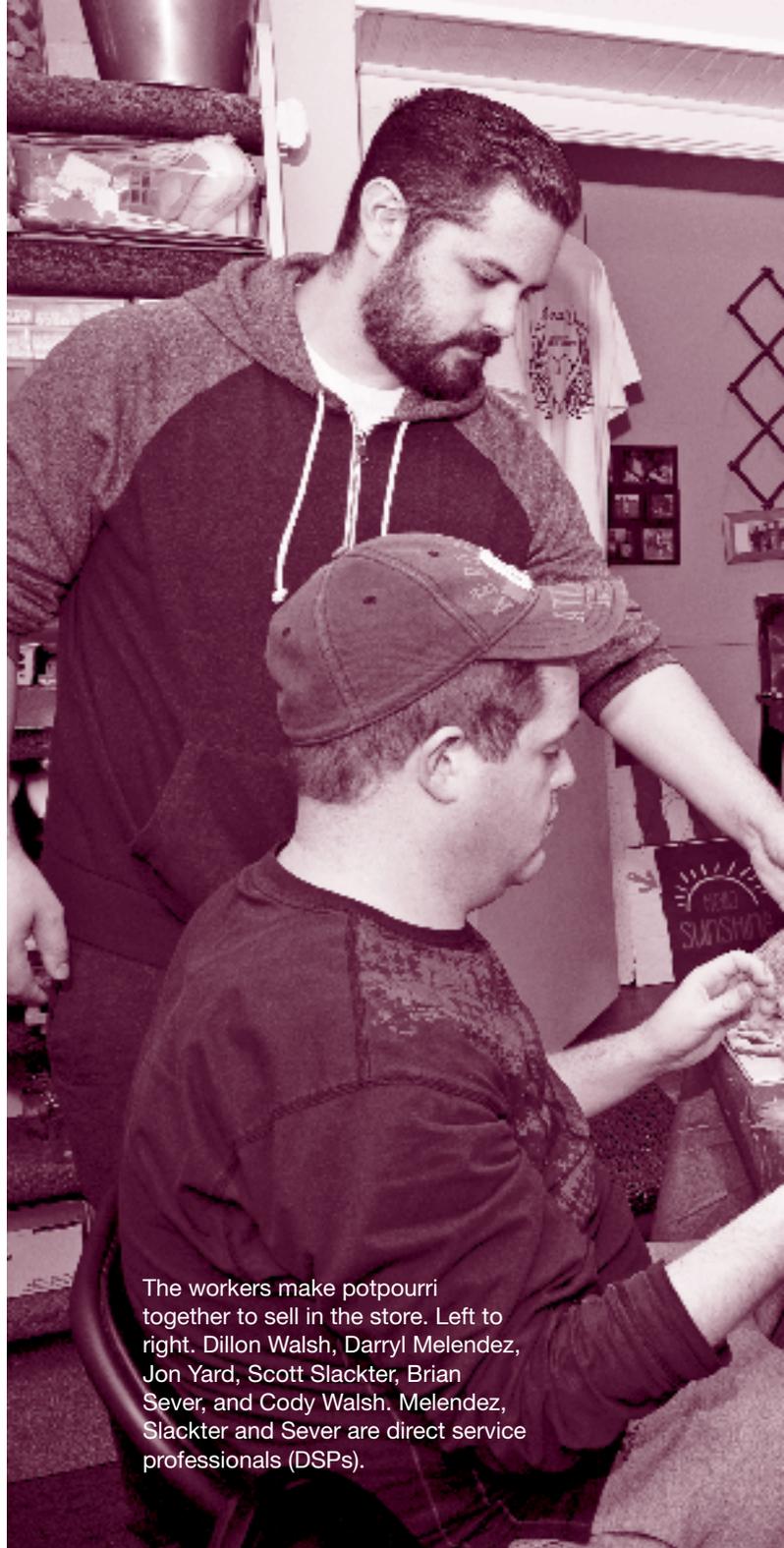
You have heard the saying, “When you get lemons, make lemonade.” What about making *popcorn*?

That is what Steven Bier did when their son, Sam, aged out of a specialized school program at 21. Knowing that the unemployment rate is 80-90 percent among those with autism, Bier and his wife wondered: where can a bright, energetic young man who views the world a little differently find work, fulfillment and happiness?

The answer was not within the adult service system, so Bier started the nonprofit, Popcorn for the People, based on Sam’s love of popcorn. When the company started four years ago as a pop-up store in Freehold, NJ, Sam was the only employee. Today, the company employs about 50 people, including more than 30 workers with autism and other developmental disabilities. Each employee is paid for their work cooking, packaging, labeling, and marketing the business.

“It is not that we rejected the adult service system and DDD. We just found that Sam was getting lousy jobs that were beneath his abilities. He was pushing shopping carts and folding towels. We wanted to see him doing something that was self-sustaining, long lasting, and more meaningful,” said Bier.

Bier noticed that when Sam began applying



The workers make potpourri together to sell in the store. Left to right, Dillon Walsh, Darryl Melendez, Jon Yard, Scott Slackter, Brian Sever, and Cody Walsh. Melendez, Slackter and Sever are direct service professionals (DSPs).

for jobs, he was often rejected because the hiring processes weren’t designed for the needs of those with autism.

“When people are empowered they are more responsible, more creative, take bigger risks and embrace accountability,” he said.

Today, Popcorn for the People is recognized



for being the only company to nationally sell a trademarked brand created by workers with autism. The brand's 14 types of gourmet popcorn are sold at the Hilton Hotel, Red Bull Arena, and Lyric Theater in Times Square, where *Harry Potter and the Cursed Child* plays.

Bier is not alone.

Consumer-Driven Social Enterprise: A Growing Trend

Across the country, a growing number of parents who view the adult service delivery system as broken are starting innovative businesses. In Denver Colorado, Tiffany Fixter, a former special education teacher and day program director, opened



Betsy Yard and her son Jon hang his jewelry in their store, Gail Force Winds.

Brewability Lab, a brewery; in Wilmington, North Carolina. Parents of two children with Down syndrome opened Bitty & Beau's Coffee, a coffee shop and café. A father in Parkland Florida, opened a car wash, Rising Tide (now, also in Margate, Florida).

These forward-thinking entrepreneurs hope to create opportunities for their adult children with I/DD that will result in long-term employment and a career ladder with community connections. While each business is as different as the individual it is created to support, they all have one thing in common: they seek to address an unmet need and change public attitudes through a market-driven approach.

Advocates of small business ownership and micro-enterprise say the benefits for people with I/DD are many. Benefits include increased range of choices and flexibility, income generation, community engagement, inclusion and integration, enhanced self-esteem, and improved quality of life. Research shows that self-employment and business ownership allows greater accommodation of disability, emphasizes an individual's strengths and interests, and leads to social and economic empowerment.

Grateful Bites café and bakery is a small business in Flemington, NJ. A project of the non-profit Ability2Work, Grateful Bites was started by “parents, doctors, CPA's, psychologists, engineers, professionals and concerned community members who know the system for developmentally disabled individuals is broken.” They strive to build a better life for their adult children and build a community that supports the cause. The restaurant uses organic quality ingredients from their gardens and local farmers.

At Grateful Bites, entrepreneurship is the cornerstone for change. Their goal is to be free of the government restrictions that separate people with disabilities from their

communities and support systems when they seek employment.

In Mercer County, NJ, Sergio & Violetta Neri started “Project Autism,” a farm-based business that now employs their 27-year-old son Davide, who has severe autism, as well as several others.

The couple came to the United States and settled in Hopewell to carry on the family tradition of winemaking. The rolling hills of the vineyard provided a safe and well-supervised environment, so the concept for “Project Autism” grew organically. Workers there build wine boxes for shipping and packaging, and also create “kindling boxes”—cardboard boxes filled with dry, well-sized pieces of wood that can be used as a starting log in a fireplace.

Project Autism has now evolved into a new DDD-approved provider agency. It is approved for job coaching, community support, transportation services, and behavior support.

“The motivation was to help our son, because we know from the inside what it is like,” said Violetta.

In 2018, Tony Lesenskyj opened We Make Autism at Work as a solution to the transition needs of his son, Colin. While the nature of work itself—assembly, packaging and shipping—is not nothing new for people with

disabilities, the workspace and business climate certainly is.

Lesenskyj converted a conventional warehouse into a nurturing, stress-free workspace. It includes everything from arcade games to big comfy couches, a basketball court and fitness equipment. Private spaces are also available on-site for employees to receive contracted services, such as speech therapy, physical therapy and counseling.

Job growth at We Make-Autism at Work is directly related to personal growth. Individuals have the opportunity to become team leaders, learn higher-skilled assembly tasks, such as electrical components of solar caps, or learn data entry using software programs such as Microsoft Excel.

Lesenskyj has been noticed by business leaders. He won the 2017 Ernst & Young Entrepreneur of the Year Award for New Jersey, in large part because of the formation of the We Make concept and business model.

Starting Early

Parents are not waiting until graduation to get the ball rolling.

Ten years ago, Jonah Zimiles and his wife Ellen opened [words] Bookstore in Maplewood, NJ. At that time, their son Daniel, who is on the autism spectrum, was only 13. The Zimiles wanted to provide an intellectual hub for Maplewood and surrounding communities. They also wanted to offer a warm, welcoming environment for families affected by developmental disabilities, as well as vocational training opportunities for individuals with autism.

“Our hope then was that one day Daniel would work at our bookstore,” said Jonah Zimiles. Today, Daniel is 23 and he works in the bookstore one morning a week.

While the number of people with developmental disabilities on the payroll at [words] fluctuates, the store provides job

training for young adults and initial opportunities for people who are in day programs.

“We have a staff member who is in charge of our program, and most of our trainees come with state-funded job coaches. We have had well over 100 individuals with developmental disabilities work in some capacity in our bookstore. Almost all of them come to us through autism schools or adult service providers,” added Zimiles.

“Our goal remains to provide relatively short-term opportunities that can then lead to permanent employment elsewhere,” added Zimiles.

“Employment options remain limited for adults with autism, especially those with more severe challenges, which is the population that we serve. That being said, great progress has been made over the past decade. We hope to partner with larger companies to help train potential employees for work in their companies,” he concluded.

With only an Etsy storefront, Julie Taylor’s small business, Ohana Swirls—Life, Art and Autism, creates crafts and felted, wearable fiber art. The Medford, NJ resident’s 15-year-old son Brandon, who has autism, produces hand-made birdhouses and cards. He also helps with packaging, shipping and other tasks. Etsy is an e-commerce website focused on handmade or vintage items and supplies.

Left Jonah Zimiles and his son Daniel working at the family bookstore Words Bookstore in Maplewood, NJ.





Daniel Zimiles puts books on shelves at Words Bookstore.

Driven by a combination of hope and fear, she started the business in order to take transition planning into her own hands.

“I did it to create independence and give him a sense of accomplishment,” she said. “I started now because we will run out of time if I don’t do something. I realized after a year of teaching him to tie his shoes that other job skills needed to start sooner for a more independent future. It’s hard to think about those things, but whether we like to think about it or not, we must lay the groundwork for when we are no longer around,” she stated.

Brandi Fishman also started early, laying the groundwork for her 10-year-old daughter, Zoe. Two years ago, Fishman opened Breaking Grounds Coffee and Cafe in Mount Holly, NJ.

“Zoe will age out at 21 and I want to be ready. It is quite terrifying,” said Fishman.

She believes that it is “a moral imperative” to provide individuals with developmental disabilities with the opportunity to improve their quality of life, gain employment and have meaningful participation in the community.

Like Fishman and Taylor, Stephanie and Mark Cartier are planning ahead for their daughter, who has Down syndrome. They started No Limits Café, a nonprofit in Middletown, NJ. It is slated

to open for business during the spring of 2019. The café will employ 20-25 adults with I/DD, all earning at least minimum wage. Beyond running the restaurant, they hope to train adults with I/DD to work in the fast-paced restaurant industry, and help place them at other area restaurants.

“I do not judge any parent for choosing a day program, but to us, it looks like babysitting. Even those who go out to work only work a few hours here, a few hours there. We want her to have a career, not a part-time job. We want her to have the same opportunities as her brothers,” Stephanie Cartier said.

“We aim to change the way employers think about our kids. That is what this is all about. We are on a mission to change the soft bigotry of low expectations,” she concluded.

Betsy Yard is also on a mission—not only to create more meaningful employment options for her son, Jon, but also to change attitudes and expectations.

In 2009, when Jon was turning 15, Yard founded Yard Work & More, Inc. Her goal was to convert the skills Jon had mastered in school—animal care, yard work, crafting, jewelry making and card making—into a flexible business that fit his needs.

What started as a unique self-directed model, grounded in person-centered desires, now includes several families. Yard refers to it as a “group self-directed model” which uses each member’s strengths and interests. Yard Work & More runs a community garden and an Etsy site. It provides funding for weekend trips, and small inclusive recreational sports.

Last year, Yard Work & More opened Gail Force Winds, a handmade and vintage co-operative gift shop in downtown Bordentown, NJ. The store offers a place for individuals to make and sell original art, crafts and other items. Those who want to, may volunteer at the co-op, greeting guests, bagging and wrapping purchases, manning the register, and arranging store displays.

“There is always something to do here,” said Yard. “I don’t care what agency is funding your

support services, or who you are, you are welcome to come and hang out. There is always a pot of coffee on, and a place to sit.”

There is no signage to let patrons know that many of the artists, craftsmen and store workers have disabilities. That is where Yard steps in.

“The moment someone picks something up from the shelf, I tell them the story of who made it. It blows their mind. In fact, the most precious thing I am doing here in Bordentown isn’t creating jobs, it’s changing minds and attitudes,” she said.

She is both inspired and frustrated.

“I see Jon as a person—not a person with disabilities. He is my son, but he is an amazing man and has so much to offer. And so do all the other people who are part of this,” she said.

“I didn’t intend to start a business. I did this because I couldn’t find what Jon needed. It didn’t exist.” What was I supposed to do? If I had not started this, Jon would be sitting at home right now,” she said.

“Yard Work and More, and the life Jon leads is a tribute to all the people who helped him—his teachers, his speech therapists his BCBA, his OT, his PT his DSPs. They worked with Jon so he could have this life,” she said.

“Parents don’t need another workshop or webinar to tell us how to use this system. It doesn’t work and no amount of training will change that. There are too many moving parts. The system is broken and the expectations are too low,” said Yard.

“For his whole life, we were always told to have high expectations. Isn’t this what we are working for when our kids are in school? I don’t remember an IEP goal that said ‘Jon will attend a day program.’ The goal was to get ready for work and a life that matters. And that is what he has,” she concluded.

Learn more and support these New Jersey-based businesses, started by parents and designed to create meaningful employment options for those with disabilities. **P&F**

Popcorn for the People

Piscataway, NJ
www.popcornforthepeople.com

Pride Paws

Medford, NJ
www.prideventuresinc.org

Grateful Bites

Flemington, NJ
www.gratefulbites.org

Gail Force Winds

Bordentown, NJ
856-986-6644

[words] Bookstore

Maplewood, NJ
www.wordsbookstore.com

Breaking Grounds Coffee & Café

Mount Holly, NJ
www.breakinggroundscoffee.com

We Make – Autism at Work

Pennington, NJ
www.wemake.works

Chance on Main

Pennington, NJ
www.chanceonmain.com

Mount Lebanon Soap Company

Port Murray, NJ
[www.etsy.com/shop/
MtLewbanonSoapCompany](http://www.etsy.com/shop/MtLewbanonSoapCompany)

Project Autism at Hopewell Valley Vineyards

Pennington, NJ
www.hopewellvalleyvineyards.com

Ohana Swirls – Life, Art and Autism

Medford, NJ
www.etsy.com/shop/ohanaswirls

Matt Valentine

Practicing Medicine with a Disability

By Maryann B. Hunsberger



Matt Valentine, physician assistant, studied at a Philadelphia coffee shop.

During a busy day of examining and treating patients at a South Jersey Emergency Department, Matt Valentine sometimes stands on his feet for ten to 12 hours straight. That's enough to make anyone's leg muscles feel fatigued. Valentine, who has cerebral palsy (CP), which causes muscle contractions and tightness in his legs, is no exception. Yet, he does his job like everyone else.

Valentine has been doing his work like everyone else for as long as he can remember. He was born prematurely and his parents were told he might have an intellectual disability. But, he earned good grades in his local public school. He moved on to college and medical school, and worked as an emergency medical technician (EMT), all the while undergoing 20 surgeries to loosen the stiff, tight muscles in his legs. His last surgery was in 2013, and he hopes he is done being on the patient side of the operating table.

The 25-year-old Cherry Hill resident became interested in medicine as a child, watching the show "ER" with his mother in their Cinnaminson home. He said being a frequent patient also made him interested in "what happens on the other side of everything."

As a high school senior, Valentine received a \$1000 scholarship for academic and extracurricular achievements and community involvement while living with a disability. He then attended Mini-Med 2011, a five-week Drexel University College of Medicine summer program. This experience confirmed that medicine was the field for him. So, he contacted Linda Duffy, a physician assistant (PA) who had treated him as a child. He learned that under the supervision of a doctor, PAs could examine, diagnose, and treat patients. They could also assist during surgery.

Valentine arranged to shadow Duffy at work during the summer before his freshman year at Rutgers University in New Brunswick. He continued shadowing Duffy during his winter and summer breaks throughout his freshman and sophomore years. Watching her work made him realize that being a PA would be a better fit for him than being a doctor. "I realized I cared more about the people side of medicine. My desire to practice medicine came from wanting to spend time helping patients. As a PA, Linda was able to take more time with her patients. She really cared about them. She inspired me."

At Rutgers, the Office of Disability Services accommodated his disability by arranging for a bus to take him to classes. They also helped him plan his schedule so he would arrive on time for those classes. As a freshman, he formed The Allied Health Professions Club for students hoping to go into allied health fields, such as physical therapy, occupational therapy, speech pathology, dietetics and for those hoping to become PAs. “There were a bunch of pre-med clubs that focused on being a doctor. Nothing was catered to being a PA. I realized that a club for other medical professions was needed. So, I thought I’d start one. The club gave us networking opportunities that we otherwise wouldn’t have had.”

Since admission to most PA programs requires prior healthcare experience, Valentine took part in an intensive training program to become a certified EMT after his freshman year of college. He began working as an EMT and ambulance driver with the Beverly Edgewater Park Emergency Squad. He did this for four years. “I wanted to expose myself to an area of medicine. I like the rush of responding to an emergency and wanted to see if I could keep a level head in an emergency. I had a little issue lifting heavy patients, but could do everything else. It was a big accomplishment for me physically, and my fellow EMTs accepted me completely. I miss being an EMT and think about doing it as a hobby on the side.”

Valentine graduated with a bachelor’s degree in public health. He was accepted to the Philadelphia College of Osteopathic Medicine on his first try, a feat only 6 to 7 percent of applicants achieve. He attributes his success to a combination of factors, including his experience as an EMT, his time spent shadowing PAs, the networking he did through the club, and taking part in a medical mission trip to Honduras with Rutgers.

He found clinical rotations to be the most exciting part of medical school. “I loved the mentorship and how they were always willing to stop and teach you regardless of how busy they were. Emergency Room was my favorite hands down. It reminded me of my EMT days. It provided me with the broadest patient base with all ages and all complaints. It kept me up on all my skills.”

Valentine said medical school only provided “maybe one lecture” on disability sensitivity.

However, his instructors and fellow students knew about his disability and were fully accepting. He gave his classmates some tips on identifying patients with CP. He said he’d like to think that his time there allowed his fellow students and instructors to see a person with a disability in a positive light. “And I’d like to think they saw that cerebral palsy, or having a disability in general, doesn’t define me. I’m much more than that.”

He had positive experiences with patients and their families during his clinicals, too. “In orthopedics, a patient’s mom was happy to see someone with CP in my position. She cried and said I gave her hope for her son, who also has CP.”

Asked if he ever felt he had to do more than others to prove himself, he said, “I think it was a big part of how seriously I took my education in general. While I couldn’t ‘prove’ myself to others physically, I certainly could academically. I think it is a huge part of why I developed a strong work ethic.”

He served as class president of the class of 2018 and graduated with his master’s degree in health sciences/physician assistant studies in August 2018.

Since graduating, he has been working as an emergency medicine physician assistant. Some of his patients have noticed that he walks with a limp and asked him about his disability. “A few of them commented on it. It’s been all positive. One time an older couple asked about it, and I was able to connect with them more easily. I’d like to think I can give people hope. If I see it can benefit a situation, I will bring it up. I don’t normally, but if I can help a patient with that knowledge, I will.”

Valentine feels he has a unique viewpoint to offer to patients. “My big fear in applying to medical school was that patients wouldn’t accept me. I thought they might not think I’m qualified or they would think I couldn’t perform my job. But, I didn’t have any negative reactions at medical school or on the job. My disability gives me a more personal connection to people. I have a limp, but it won’t stop me from helping people and providing the best care. I’d like people with disabilities who are reading this to go for their dreams. It might be scary, but there isn’t any reason to not try. If you work hard enough, you can accomplish a lot.” **P&F**

Profile

Family Support Leadership Eileen Hurley & Gabrielle Bohon

By Jonathan Jaffe

The Statewide Family Support Planning Council is the ideal organization to bring together parents and family members of people with developmental disabilities, who can easily exchange knowledge and information about family support services.

The strength of this council is its ability to reach into all areas of the state, as the New Jersey Council on Developmental Disabilities (NJCDD) coordinates 10 regional councils in accordance with the 1993 Family Support Act.

As members advocate for families and individuals with developmental disabilities at the local level, regional councils collaborate through two new statewide council leaders: Eileen Hurley and Gabrielle Bohon.

Both volunteers are the mothers of people with developmental disabilities, and both have been advocates for their children at the local level for many years. Hurley became engaged in the Statewide Family Support Planning Council through the NJCDD's Partners in Policymaking program, which exposed her to many initiatives underway throughout New Jersey. Bohon was invited

by a friend to attend a Regional Family Support Planning Council #1 meeting.

Below, these two leaders discuss why they became involved on such a prominent level. They also share their goals for their two-year terms at the helm.



Eileen Hurley and her son Colin at their home in Cedar Grove NJ

Eileen Hurley

Hurley, who serves as chair, believes she and Bohon make the perfect team.

Hurley said her focus is the interests of older people with developmental disabilities, while Bohon—who has a 19-year-old daughter—is working with younger families to ensure that individuals can easily transition from the public school system to life in the community.

Hurley, of Cedar Grove, has a 27-year-old son, Colin, with autism and other developmental disabilities. Since he was a young boy, she has been

active in various autism awareness groups, such as Autism Speaks and Autism New Jersey, and assisting with fundraisers.

She became involved in the NJCDD in 2013, when she signed on the Partners in Policymaking program. She graduated in May 2014.

“I went through that class when Colin was exiting the school system,” she said. “He was out in the real world and it was imperative for me to get involved. I saw that there wasn’t much out there as far as quality programs for my son for his level of needs. Upon graduating from Partners in Policymaking, I wanted to advocate for better services for Colin and other adults.”

Then, Hurley joined her regional planning council in Essex County. At the statewide level, she chaired the Public Relations Strategies Committee, launched the Facebook page and managed the creation of promotional videos highlighting the mission of the regional councils.

“I have been able to foster so many friendships with people, creating a support system,” she said.

“People within this support system truly ‘get’ you and your plight. You also help others, as well.

It has been truly inspiring for me. There’s been a lot of good when we all come together.”

Gabrielle Bohon

The first time Gabrielle Bohon considered herself a “disability advocate” was when her daughter, Lily, was born 19 years ago with Down syndrome.

The Boonton mom, an estate planning attorney, is now taking her grassroots work to a state level, accepting the role of vice chair of the Family Support Planning Council. Always a vocal advocate for her daughter, she has been involved on the state level for the last eight years.

Bohon remembers her first steps as a disability advocate when she learned during pre-natal testing that Lily had Down syndrome. In looking for care, the family was introduced to an early intervention program, known as Stepping Stones, now in Roseland.

“The program taught us about the disability, the rights we had as her parents and helped prepare us for Lily’s school years,” Bohon said. “Lily was in-district from the beginning, and I was able to meet with other moms. We started our own grassroots outreach program to share information and to run recreational programs.”

Bohon recalled that the parents group taught children to be mentors for other kids who required special education. “It evolved into a Special Education Advisory Group that all school districts are supposed to have,” she said.

Still a teen, Lily remains part of the Boonton Public Schools, but she is placed out-of-district at the Career & Community Studies program at the College of New Jersey in Ewing, where she is enrolled in a non-matriculating life skills/social skills program. There are only 40 students in the entire four-year program, which accepts 10 additional students each year.

“Lily gets to interact with non-disabled peers in a college setting and also gets many academic opportunities,” Bohon said. “We don’t believe education stops when you turn 18. This program gives her

the opportunity to be around young men and women, up to age 25, in a typical college setting.”

Bohon said she also serves on the NJCDD’s Children and Youth Subcommittee, designed to educate parents about how to seek services from the public schools, and early intervention, as well as to engage parents who can often feel isolated.

“It’s good to talk with people who have already lived through what you are going through,” Bohon said. “Eileen and I want to make sure people don’t feel alone.” **P&F**



Gabrielle Bohon and her daughter Lily at the local park in Boonton, NJ where Lily works during the spring and summer

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

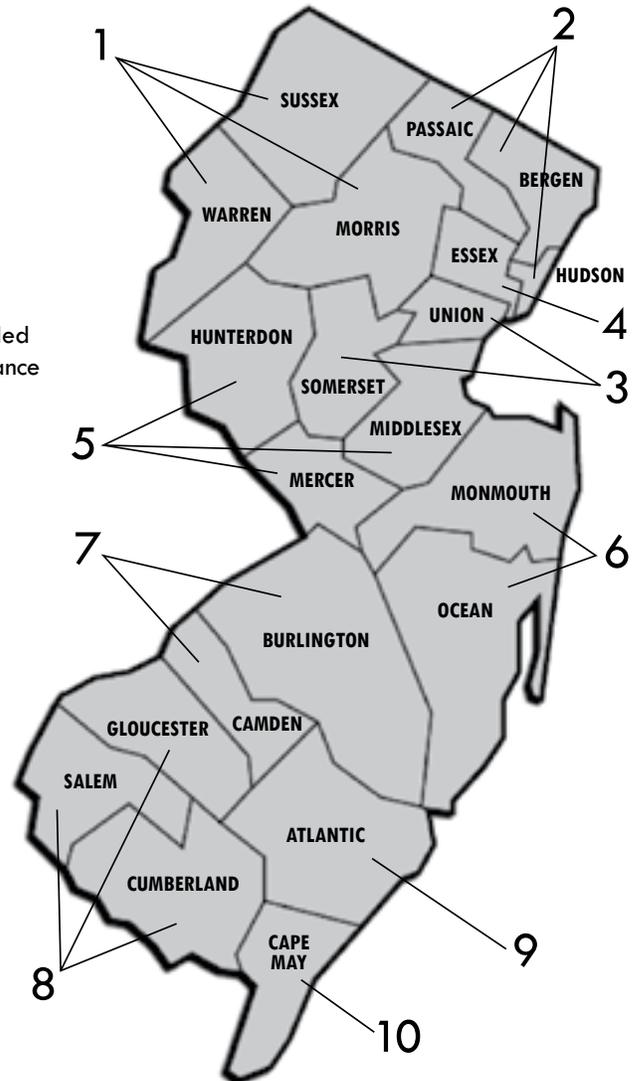
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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' website 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
Vice-Chair: Gabrielle Bohon

Meets the third Tuesday of each month
at Wegmans Market Cafe
34 Sylvan Way
Hanover, NJ 07054

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
Co-Chairs: Frank Fiore, 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: Phyllis McNair
Co-Chair: Eileen Hurley

Meets the first Wednesday of each month
Bloomfield Civic Center Music Room
84 North Broad St.
Bloomfield, NJ 07003

7:30 p.m.—8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

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

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

Lakewood Municipal Bldg.
231 Third St., 2nd floor
Lakewood, NJ 08701

7:30 p.m.—9:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
e-mail: rfspc7@gmail.com
Chair: Laura Kelly

Meets the fourth Thursday of each month

Cherry Hill Public Library; Main Floor
1100 Kings Hgwy North
Cherry Hill, NJ 08034
11:30 a.m.—1:30 p.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

Arc of Atlantic County
6550 Delilah Rd., Suite 101
Egg Harbor Twp., NJ 08234

Meeting times and dates TBD

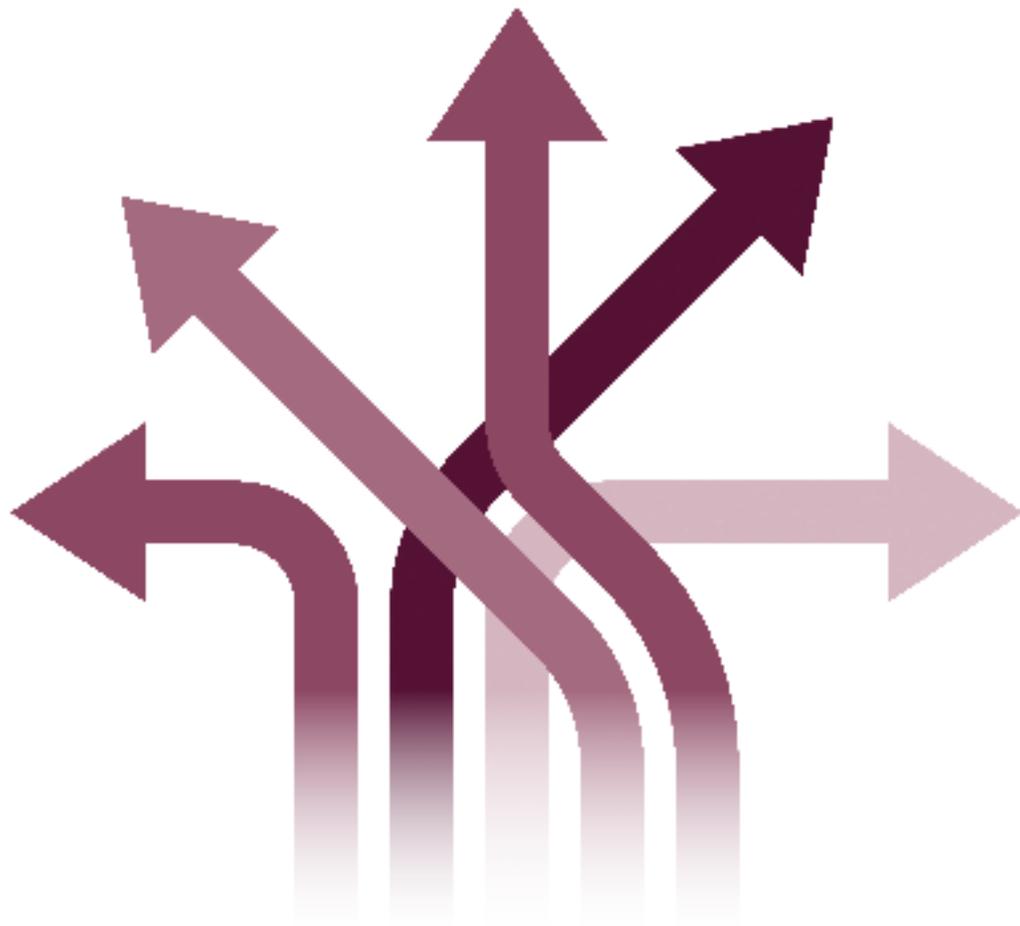
10 CAPE MAY

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

Meets the third Thursday of each month
during Oct., Feb., April, and June

Cape May Special Services School
148 Crest Haven Dr.
Cape May Court House, NJ 08223

6:30 p.m.—8:00 p.m.



Supported Decision-Making Enhancing Quality of Life

By Jonathan Jaffe

It is commonplace in New Jersey for people with disabilities to follow the edict of their legal guardians. Where they live, work, shop and recreate has all required the formal approval of someone else.

It is not to say guardians don't have the person's best interest at heart when they make decisions. But some disability advocates are now asking if there is a viable alternative, in which people with intellectual and/or developmental disabilities (I/DD) can have more of a say in how they live.

Joseph Young, former executive director of Disability Rights New Jersey, pointed to a new movement that is gaining a foothold across the

United States. It is called "supported decision-making," in which people with I/DD are given much more of an opportunity to self-direct.

This concept has been evolving in other countries for more than a decade. Several countries have long found that everyone—including individuals with disabilities—have the legal capacity to make their own decisions.

This concept was further advanced when the United Nations Convention on the Rights of People with Disabilities voted in 2006 to adopt a resolution stating that "persons with disabilities enjoy legal capacity on an equal basis with others

in all aspects of life” and that “[all] parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

In places like Alaska, where this movement is taking root, people with I/DD are signing “supported decision-making agreements” (SDMAs), which are written documents that allow others to help direct their lives. Supported decision-making is not about mandates. Rather, it is about helping someone make the most of personal of choices.

“New Jersey practices a very traditional kind of law,” Young said. “Attorneys know about legal guardianship, but there is not much information in this state about supported decision-making.”

Young said he has been speaking about the need to create a pilot program in the state, in conversations with the New Jersey Council on Developmental Disabilities and the Boggs Center on Developmental Disabilities.

“We are in the nascent stages of this pilot, with every expectation that it will happen,” he said.

Colleen McLaughlin, the Community Training & Technical Assistance Manager at The Boggs Center, said the organization has hosted three lectures on supported decision-making in recent years, in the hopes there will be a formal collaborative pilot, now “in the explorative phases.”

McLaughlin notes that individuals from the Boggs Center, as well as Young, have taught courses on supported decision-making at the Rutgers School of Social Work. “We have been gradually infusing the concept, bringing in internationally-recognized experts through our lecture series,” she said.

There is an open mind in New Jersey to supported decision-making, at least in some circles.

Those with a supported decision-making agreement have “supporters,” not guardians. These supporters encourage independence, guiding people with disabilities through the many choices they have and encourage them to try out new things.

Paul Aronsohn, the state ombudsmen for people with developmental disabilities, said guardianship is certainly one of the most important, most consequential issues. He said there has been no formal push for supported decision-making, but it appears “more people are exploring it.”

“Decisions regarding it should never be taken lightly or without full information about its implications as well as other options available to individuals and their families,” he said. “From supported decision-making to general guardianship, there is a full spectrum of options that should be considered.”

He added: “Although full guardianship is sometimes necessary, we should always explore other options that could allow the individual to remain as independent as possible.”

Jonathan Seifried, Assistant Commissioner for the Department of

Human Service’s Division of Developmental Disabilities, said the state is in obvious favor of the least restrictive arrangement for those it serves.

“We believe this promotes self-determination and maximizes personal autonomy, leading to improved quality of life,” Seifried said. “Educating individuals and their families about supported decision-making is something we support.”

Those with a supported decision-making agreement have “supporters,” not guardians. These supporters encourage independence, guiding people with disabilities through the many choices they have and encourage them to try out new things. Supporters can attend meetings or appointments, helping out whenever they can. And they can step back, when needed.

Young said supported decision-making is a stark difference from legal guardianship, in which lawyers and others are free to make unilateral decisions without truly learning what a person with I/DD wants or needs to be fulfilled. There

needs to be a steady shift, promoting self-determination, control, autonomy and as much independence as possible, he said.

Legal Help

A vocal proponent in this effort has been the Center for Public Representation (CPR), a public interest law firm serving people with disabilities for more than 40 years. In 2014, CPR launched a pilot program in western Massachusetts with 10 participants being served through Nonotuck Resource Associates, a social service provider for people with I/DD.

“By partnering with an expert in working with people with disabilities, we were able to stay true to the values of supported decision-making, promoting independence and autonomy,” explained Anna Krieger, an attorney with CPR. “The pilot has since expanded. We are working with a total of five agencies, and now with 25 participants.”

CPR, whose work is subsidized by grants, handles all the legal work and the “big picture thinking” of how to create supported decision-making agreements that are most effective for the individual, the attorney said.

“We work with people on signing health care proxy forms and power of attorney if they have assets that need to be protected,” Krieger said. “We talk to families about the process and what they can expect. We do training for other agencies to do the same work we are doing, so that eventually CPR can pass off the work as more and more people become involved.”

According to a 2010 estimate by the National Center for State Courts, there are at least 1.5 million adults in the United States under guardianship, but the number could be as high as 3 million, given the remarkable dearth of data.

The number of individuals with I/DD under guardianship is expected to increase over the next few decades.

Because of enhanced medical care, many people with I/DD will outlive their parents and family caregivers. Data from CPR suggests that by the year 2030, there will be several million individuals over 60 years old with intellectual disabilities in the U.S. who will be at risk of guardianship.

“We’ve learned how transformative supported decision-making is for people with disabilities,” Krieger said. “We didn’t expect it to be such a dramatic experience. We’ve found that people became empowered, and finally have control over their lives and the decisions that need to be made.”

CPR is launching a similar pilot program in New York.

Around the Nation

Texas was the first state to pass a law that allowed for supported decision-making as an alternative to legal guardianship in 2015, said CPR attorney Bob Fleischner. Other states have followed, beginning with Delaware and then Wisconsin, then Missouri and Alaska. Washington D.C. also has a law that requires students who reach 18 years to consider supported decision-making as opposed to legal guardianship.

Fleischner noted there are now legislative proposals in Maine, Indiana and Rhode Island. There was also a proposal in Tennessee, but it did not pass the State Legislature.

Jonathan Martinis, a senior director for law and policy at the Burton Blatt Institute at Syracuse University, said he has been involved in disability law for 20 years, but has never seen a movement catch on as quickly as supported decision-making.

“Just in the last five years, you are now seeing states enacting laws,” he said, noting he made a presentation in the spring at the Boggs Center in Piscataway, also attended by representatives of Disability Rights New Jersey and the New Jersey Council on Developmental Disabilities.

Martinis noted that state laws are not necessarily required for people with disabilities to select supported decision-making over legal guardianship.

Under disability law, he said, people with disabilities should be permitted to live in the least restrictive environment. “I tell a lot of state officials that I am in favor of laws, but I feel this is more of a cultural issue,” Martinis said. “We need to change the prevailing culture that legal guardianship is the first and only alternative.” **P&F**

MYTH BUSTERS

Fee-For-Service System

By Brenda Considine

In this new feature in *People and 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 officials and advocates.

MYTH #1: *Managing services through fee-for-services is fairly simple. Most families find it easy.*

FACT: The transition to fee-for-service has been complex with many moving parts. While some parents learn the ropes quickly, others feel overwhelmed, frustrated, and confused. Some parents report feeling like they need more training in order to manage the system. Families should rely on their support coordinator to help familiarize them with the new fee-for-service system. Families should also use DDD helpdesks and NJCDD Regional Family Support Planning Councils.

MYTH #2: *In order to get enough services, an individual needs a big budget.*

FACT: Individual budgets for adults with intellectual and developmental disabilities (I/DD) in the fee-for-service system are based on the results

of the New Jersey Comprehensive Assessment Tool (NJ CAT). By completing the NJ CAT accurately without overestimating their child's abilities, most individuals are assigned to a level of funding that can meet their needs appropriately.

MYTH #3: *Once an individual is assigned a NJ CAT level, there is nothing they can do.*

FACT: The tier level assigned through the NJ CAT is based upon the responses provided. If it is felt that there has been a change in the person's abilities since the NJ CAT was completed or that the responses were not accurate the guardian can work with their support coordinator to request another NJ CAT assessment.

MYTH #4: *When a student leaves the educational system, they will be able to use their budget to purchase most, if not all, of the services and supports they received while in school.*

FACT: Once a student ages out of special education at the age of 21, entitlement to a free and appropriate public education ends. School districts are not permitted to place a budget cap on the cost of services, nor are there caps within funding categories (e.g., transportation, related services, etc.) Even with an adequate budget, individuals in the DDD fee-for-services system may not

be able to secure—or even find—the same level or quality of services they were getting from the school system.

According to Lisa Parles, Esq., a disability rights attorney with Parles Rekem LLP, the transition from school to the adult world for those with challenging behaviors is a particular challenge.

“The funding levels drop dramatically, often accompanied by a reduction in staffing ratios. Many individuals’ behavior intervention plans cannot be effectively implemented without proper staffing, and we frequently see a deterioration of behaviors,” said Parles.

MYTH #5: *Fee-for-service offers more freedom and choice than traditional DDD services.*

FACT: While it is true that many individuals have more choices in fee-for-service than they had in a traditional program, the choices are limited by where a person lives and the nature of their needs. For example, those living in rural areas may find limited program options, or they may find that certain services are unavailable. Sometimes, a person’s budget does not cover everything he/she may want or need.

“There is a paucity of adult programs capable of successfully serving individuals with maladaptive behaviors. It is a major capacity problem,” said Parles.

MYTH #6: *Transportation is included with a day program.*

FACT: This is true. Day programs provide transportation within a ‘catchment area’ determined by the service provider agency.

MYTH #7: *If an individual lives outside the catchment area, they cannot attend that program.*

FACT: According to DDD, this is not true. However, the special needs attorneys we asked took a deeper dive into the question.

“From a legal standpoint, it is possible for families to access services if they live outside the catchment area, but from a practical standpoint, transportation can be a major barrier,” said Maria Fischer, Esq., a special needs attorney with Hinkle, Fingles, Prior and Fischer. “Some families opt to drive their adult child to a day program simply because the cost of transportation is prohibitive,” she said.

MYTH #8: *The fee-for-service system has expanded the range of transportation options and choices.*

FACT: The high cost of transportation limits the affordability of other services including day programs. Families and support coordinators report that transportation continues to be a huge barrier. Many times, individuals choose programs closest to their home because they do not have transportation options. Those who need accessible transportation have an even greater difficulty. For many people, a great deal of the budget is used for transportation costs.

MYTH #9: *If an individual changes support coordinators, they must start their plan all over.*

FACT: Individuals can change support coordinators at any time. When a person changes support coordinators, the existing plan goes to the new support coordinator.

MYTH #10: *Families should rely on their support coordinator to choose the best services for them.*

FACT: Support coordinators should not choose services for the individual. The quality of support coordination varies greatly, and many support

coordinators are new to their jobs. While a good support coordinator should provide options and information, the individual, guardian or family must research services and providers, and choose the right fit.

MYTH #11: *Individuals who accept the supports program while on the waiting list for housing, are taken off the list and have to start the process over again.*

FACT: Leaders at DDD clarified that there is not a ‘housing waiting list’ per se. Rather, the ‘Community Care Program Waiting List’, also known as the ‘Priority Waiting List’, is the list for individuals who are waiting to be evaluated for the Community Care Program. Once an individual is reached on the Priority Waiting List, and is found to be eligible for the Community Care Program, they will be enrolled and can receive a housing voucher. Any individual on the Priority Waiting List may enroll in the Supports Program without being removed from or losing their place in line on the Priority Waiting List. DDD is currently contacting individuals on the Priority Waiting List to offer enrollment in the Supports Program.

MYTH #12: *Residential provider agencies can require parents to give up being the representative payee for their adult child's Social Security, and switch it over to the agency.*

FACT: DDD confirmed that this is *not* allowed. SSI payments to people with I/DD are an entitlement. Most of the time, parents are representative payee. The individual may keep a ‘personal needs allowance’. The provider agency will determine how much of the balance must be submitted as contribution to care.

“Some providers have told parents that they must give up being representative payee, but they cannot require it. When a parent challenges this, the provider has no legal standing, unless the parent

is misusing funds,” said Paul Prior, Esq., also with Hinkle, Fingles, Prior and Fischer.

MYTH #13: *Gym memberships and personal trainers are not allowed under fee-for-service.*

FACT: According to DDD, reasonable gym membership costs are an allowable service that can be approved and paid for under fee-for-service. An individual’s support coordinator can assist with adding this service to the Individual Service Plan. Personal training, however, is NOT currently an approved service.

Many families and special needs attorneys report that gym memberships have not been approved.

“Gym memberships should be approved under ‘goods and services’ without question,” said Fischer. “Federal Medicaid rules clearly allow for other health-related and preventative care.”

MYTH #14: *Money from the ‘goods and services’ portion of a person’s budget cannot be used for services when the provider of those services does not serve the general public.*

FACT #1: Leaders at DDD turn to their Supports Program and Community Care Program policy manual which states:

“All providers of goods and services must exist primarily to serve the general public. If a provider exists primarily to serve individuals with disabilities, that provider must become a Medicaid/DDD approved provider for other services.” (Section 17.9.3).

For example, under this definition, the goods and services budget *can* be used for a yoga class when the provider exists primarily to serve the general public, and when the yoga studio serves all individuals. A yoga studio that serves only people with disabilities, would not be covered.

FACT #2: Denials of goods and service requests can be appealed.

Prior believes this question requires more inquiry.

“Here, DDD has interpreted a federal Medicaid rule; each state can do this. The federal rule requires ‘maximum community involvement and integration.’ The decision needs a more nuanced analysis because the answer hinges on questions like:

‘Does the setting provide sufficient opportunity for inclusion or community integration? Does the provider offer sufficient opportunities for participants to interact with typical individuals or the general public?’

Prior suggests that providers who serve only those with a developmental disability should not automatically be disallowed.

“When seeking lessons at a special needs dance school, for example, one should ask: ‘Do they offer community-based experiences, such as public performances?’

MYTH #15: *Individuals can get one-to-one nursing services at a day program through fee-for-service.*

FACT: DDD indicated that one-to-one nursing (private duty nursing) is not a DDD-covered service, but a person *can* receive nursing services at their day program if they have an assessed need through their NJ CAT, and if the day program provider is able to provide the service.

Attorneys interviewed for this story agree, but stress that it is an area that needs advocacy. According to Fischer, one-to-one nursing is usually provided under a different Medicaid Waiver—the Managed Long Term Services and Supports (MLTSS, formerly Private Duty Nursing Services). The challenge is that a person cannot be on two Medicaid waivers at the same time. A person can be in the Supports Program and have acuity. The acuity rate can offer nursing services, therefore a person with acuity on the Supports Program can access nursing services from a day program that can provide the service.

MYTH #16: *When an individual is absent from their day program, the provider will be paid.*

FACT: DDD leaders confirmed that under the fee-for-service system, reimbursement is made to day program providers *only* when a service is delivered. That means the person must attend in order for providers to be paid. Day program providers bill in 15-minute increments, so if an individual attends only for a half day, the day program is paid only for that time.

MYTH #17: *There are no attendance requirements for adults enrolled in day services through a provider agency.*

FACT: According to DDD, a provider of day program services may disenroll an individual if they are absent frequently. However, DDD encourages providers to plan for absences in their fiscal planning.

Special needs attorneys confirmed that while this does occur, a provider cannot disenroll an individual without a meeting. “There are appeal rights under Medicaid and the person has the right to services pending the appeal,” said Fischer.

Fischer added that some providers are asking parents to sign a waiver or agreement regarding discharge from a program without notice and with or without cause.

“Parents should not sign any agreements to notices that allow them to waive notices and rights. You cannot sign away your rights to Medicaid appeal,” she concluded. **P&F**

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*.

PEOPLEFIRST

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Betsy Yard is the owner of Gail Force Winds in Bordentown, NJ. She is the mother of Jon who works at the store with her. In front of Gail Force Winds store in Bordentown, NJ. Left to right- Dillon Walsh, Jon Yard and Cody Walsh. The store is named after Cody and Dillon's mother Gail who died in a car accident.