

FALL 2018

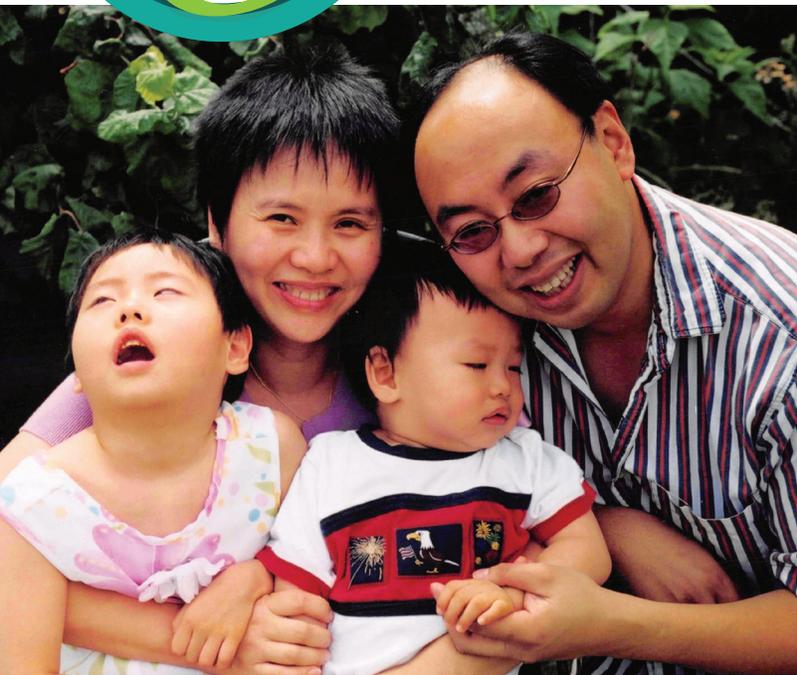
# People & Families

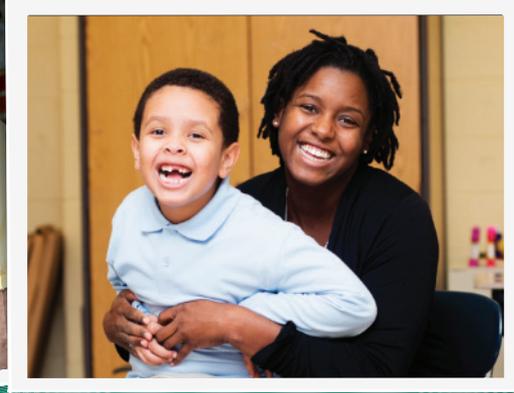
NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES



## The Family Support Act

Preserving, Strengthening, and Maintaining The Family Unit





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FAMILY SUPPORT  
PLANNING COUNCILS

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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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### Collaborating to Make NJ a Better Place for People with Disabilities and their Families

The Family Support Act of 1993 acknowledges that individuals and families know best when it comes to the supports and services they need. The NJCDD continually seeks self-advocate, family, and stakeholder input to strengthen our service system to make NJ a better place for all individuals with disabilities and their families.



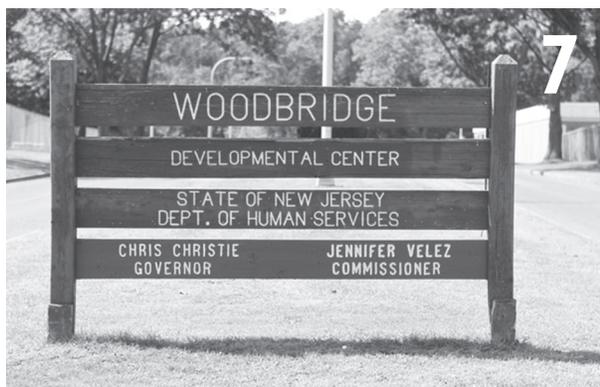
## 14 NEW JERSEY INTRODUCES FIRST OMBUDSMAN FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

On April 16, 2018, NJ Governor Phil Murphy appointed former Ridgewood, NJ Mayor Paul Aronsohn as the state's first-ever ombudsman for people with intellectual and developmental disabilities. The Ombudsman is tasked with a host of responsibilities, most important of which is to serve as a source of information for people with developmental disabilities.



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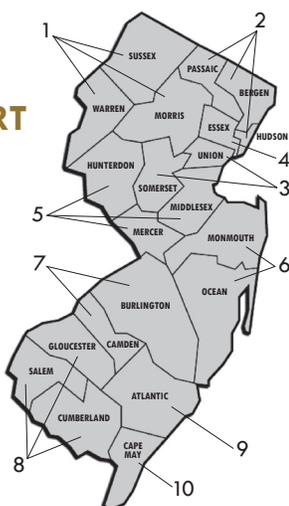
Families, consumers, providers, support coordinators, and advocates are adjusting to the changes brought about by DDD's new "fee-for-service" system. As the agency shifts from a contract-based system of funding services to a Medicaid-based, fee-for-service system, some are finding this to be a welcomed change—while others are finding it much harder to maintain their level of services.

## 24 INDEPENDENT LIVING OPTIONS FOR ADULTS WITH DISABILITIES

Since 2017, DDD has been making rental subsidies available to eligible individuals. These subsidies are being distributed in the form of housing vouchers through the Supportive Housing Connection (SHC). The goal of the SHC is to provide expanded access to affordable housing for NJ residents with disabilities by combining all of DHS's rental subsidy resources into one location.



## 26 INFORMATION ABOUT FAMILY SUPPORT



## 34 JAKE'S PLACE: A PLAYGROUND THAT ALL CHILDREN CAN ENJOY

In October of 2007, the family of Jacob Cummings-Nasto bid farewell to their 2-year-old boy, after his fourth open-heart surgery. Jacob was born with half a heart, a rare birth defect. In his short time here, Jake loved visiting parks and playgrounds near his home in Pennsauken, NJ. To honor his memory, Jake's family created a playground that any child—including those with physical and developmental disabilities—can truly enjoy.

## 28 COVER STORY CELEBRATING 25 YEARS OF THE FAMILY SUPPORT ACT

When it was signed into law in 1993, the Family Support Act marked a turning point in the history of disability policymaking in New Jersey. For the first time ever, decision-making was placed in the hands of families. The history of the Family Support Act is a study in grassroots organizing. Now, we look back with appreciation of the monumental efforts of advocates to establish this landmark legislation.

## 37 NEW WHITE PAPER SHEDS LIGHT ON CHALLENGES AND OPPORTUNITIES FOR MANAGED LONG-TERM CARE

On June 28, 2018 ANCOR published a new white paper examining the impact of Managed Long-Term Services and Supports (MLTSS) programs on individuals with intellectual and developmental disabilities. The NJCDD's public policy coordinator, Robert Titus, give his analysis of ANCOR's report.

### Front Cover

Cover photos courtesy of the New Jersey Council on Developmental Disabilities

from the Executive Director ■

## Collaborating to Make NJ a Better Place for People with Disabilities and their Families

Thank you all for welcoming me as the New Jersey Council on Developmental Disabilities' (NJCDD) new executive director. I appreciate your warm welcome. I am delighted to join the NJCDD at a time when new and exciting opportunities lie ahead.

Starting my career as a direct support professional almost 38 years ago gave me a unique perspective. My first assignment included assisting three men who collectively lived more than 150 years in a state institution. They eventually moved to an apartment in Plainfield, NJ where they lived the rest of their lives.

Their community living experiences remind me that individuals with intellectual/developmental disabilities (I/DD) are contributing citizens in our communities. We all benefit from living and working together.

Little did I know when starting my career that I would eventually rely on the state's social service system for my daughter, Tina. She was 16-years-old when a major medical event occurred. After eleven months in the hospital, we returned home with private duty nurses and a frightening view of the future. Thankfully, Tina made progress with extensive therapy. She still relies on dedicated direct support professionals who help her live the life she chooses. I regularly draw upon my experiences with Tina's acute care needs and daily challenges when listening to individuals with I/DD and their families.

As we celebrate the 25th Anniversary of the Family Support Act of 1993, we are reminded that when advocates work together, we can make monumental positive changes in our communities throughout the state. The Family Support Act acknowledges that individuals and families know best when it comes to the supports and services they need. This acknowledgement must remain a focus for everyone.

The NJCDD is guided by a Five Year Plan (2017-2021) developed through stakeholder input.

This plan focuses on:

1. Self-Advocate and Family Training and Information
2. Direct Support Staffing Issues
3. Special Education Advocacy
4. Employment
5. Transportation
6. Health and Wellness
7. Housing

The NJCDD addresses these targeted areas through systems change and capacity building efforts that promote self-determination, integration and inclusion for people with developmental disabilities. Meeting with self-advocates, families and stakeholder groups continues to be a priority. There is so much to learn from people using services and even more to learn from those struggling to access services.

During the past year, the New Jersey Developmental Disabilities Advocacy Network (DDAN) has been prioritizing a collective agenda with the state's advocacy and provider groups as well as other system partners. While several DDAN issues align closely with the NJCDD's Five-Year Plan, the following additional items call us to work collaboratively to address barriers to accessing services:

- Medicaid Threats
- Adequacy of System Funding
- Communication
- Health, Safety and Quality Assurance
- Person-Centered Self-Directed Services

I look forward to learning more about your successes and obstacles so that we can continue to strengthen our service system while making New Jersey an even better place to live for all individuals with disabilities and their families.

*Mercedes Witowsky*  
*Executive Director*

*New Jersey Council on Developmental Disabilities*

# Congress Weighs Reauthorizing Program that Moves People Out of Institutions

By: Courtney Perkes

From: DisabilityScoop.com – September 10, 2018

Following an initial vote in Congress, advocates are hopeful that a federal program aimed at helping people with disabilities move from institutions to community living will be renewed.

A health subcommittee in the U.S. House of Representatives advanced legislation late last week reauthorizing the Medicaid Money Follows the Person program for one year with \$450 million in funding.

Since its inception more than a decade ago, states have received roughly \$3.7 billion through the program to help more than 88,000 people leave nursing homes or other institutions in favor of their own apartment or a small group home.

However, Money Follows the Person expired in September 2016 and states have been running out of funds ever since.

The subcommittee vote Friday approving legislation known as the EMPOWER Care Act, H.R. 5306, was a step toward a

full vote on the House floor to renew the program.

“The reason it’s so important we get this passed by the end of the year is that, maybe with the exception of one or two states, every (Money Follows the Person) program will be out of money by the end of this year,” said Nicole Jorwic, director of rights policy for The Arc. “Some states have already started to wind down their program. Hopefully, this momentum will be a good signal to states to stop doing that.”

Money Follows the Person has resulted in government cost savings as people move out of expensive facilities, according to a federal report.

States have used the funds to pay for services not normally covered by Medicaid, such as hiring housing specialists and providing employment assistance.

Sarah Meek, director of legislative affairs at the American Network of Community Options and Resources, or



ANCOR, said Money Follows the Person has resulted in better quality of life not only for participants but for people with disabilities who are at risk of institutionalization. She said they also have benefited from housing and job services put in place.

“Access to affordable housing continues to be one of the biggest barriers to transitioning people to the community,” Meek said. “Once (states have) hired a housing counselor, they’re able to work with people who may be looking at a limited number of options.”

Curtis Cunningham, vice president of the National Association of States United for Aging and Disabilities, testified before the House subcommittee last week, saying that states need certainty of the program’s future to test new transition practices that can take several years to evaluate.

“Our members across the country have seen great value from the program, and the interventions have become more effective as states have

experimented with and learned from innovative ways to provide these supports,” Cunningham said.

Jorwic from The Arc said people with disabilities across the country are in limbo.

“There are people who are waiting and want to move in every state but because the (Money Follows the Person) program doesn’t have the funding, or in some cases has closed completely, those individuals are languishing in segregated settings outside their communities,” she said. “We’re talking about people’s lives.”

The House legislation was introduced by Reps. Brett Guthrie, R-Ky., and Debbie Dingell, D-Mich. Companion legislation has also been introduced in the Senate.

“We are very pleased with the wide bipartisan support of this bill and working hard to get this passed before the end of the 115th Congress,” said Lauren Gaydos, a spokeswoman for Guthrie.

The bill must now be marked up by the House Energy and Commerce Committee before it can go to a vote in the House.



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# Murphy Gives Go-Ahead for NJ to Sell Former Developmental Center to Woodbridge

By: Brent Johnson

From: NJ.com — August 18, 2018

The state of New Jersey will soon get \$5 million from its sixth-largest town for a piece of land that housed an institution for individuals with disabilities closed by Gov. Chris Christie four years ago.

Gov. Phil Murphy signed a law Friday authorizing Woodbridge to buy the 54 acres of land where the Woodbridge Developmental Center used to sit in the Avenel section of town.

The law (A4065) authorizes the state treasurer to allow the sale.

The state Department of Human Services under Christie closed the 50-year-old facility in 2014 as part of the then-governor’s push to develop more privately-operated community housing and rely less on expensive state institutions. Christie’s administration also shuttered the North Jersey Developmental Center in Totowa that year.

Woodbridge Mayor John McCormac said he’s not “100 percent sure” what the township will do with the land. But he said it will have “commercial, educational, and health-care components” and will not include housing of any kind.

McCormac—a former state treasurer and former member of Murphy’s transition team—said



town officials have “talked to potential interested parties.”

Christie defended closing the facilities despite some opposition. He said he was shocked to learn New Jersey was second only to Texas in the number of large institutions it operates and the number of people with intellectual and developmental disabilities who live in them.

“I cannot sleep at night knowing I’m institutionalizing people by my hand as the governor,” Christie said at the time.

The state declared the Woodbridge land surplus.

Its sale will be only a drop in the bucket of New Jersey’s \$37.4 billion state budget.

# Clothes for People with Disabilities Highlighted on Catwalk

By: Ragan Clark

From: New Jersey Herald — September 6, 2018

NEW YORK (AP)—New York Fashion Week has opened its glamorous tent wider to feature models with disabilities wearing adaptive clothing designs by Tommy Hilfiger, Nike and Target.

Organized by the Runway of Dreams Foundation, the show on Wednesday included a catwalk welcoming to wheelchairs, crutches, walking canes and more. Actor and model RJ Mitte of “Breaking Bad” was host.

Mitte said he understood the importance of inclusion on a personal level, having been diagnosed with cerebral palsy at age 3. “I’m really excited to see all this inclusivity and all of these strides to be diverse,” he said.

The founder of Runway of Dreams, Mindy Scheier, was inspired to start her foundation when her son, Oliver, who has muscular dystrophy, told her he wanted to wear clothes like everyone else. His request was for blue jeans—a clothing item that would prove difficult to pull on and off with his condition unless the pants were modified. She decided to make him an adaptive pair on her own and realized the need for more adaptive clothing lines for individuals with disabilities.

“Fashion is a direct correlation to how we feel about ourselves, our confidence, our self-esteem,” said Scheier. “And if you don’t have that, if you

don’t have options, it can really affect how you feel about yourself. So truly, clothing is a basic need. So, shouldn’t we all feel really good and have options like everybody else?”

Model Mama Cax, recently featured on the cover of Teen Vogue’s September issue for “The New Faces of Fashion,” lost her leg during a battle with cancer. She is now an advocate for inclusion in the fashion industry and walked the runway Wednesday.

She said she wanted to see people with disabilities cast in movies and TV in lead roles or as love interests but without any “inspiration piece attached to it,” adding: “We want to see them in a normal role,

average role, like we do in our everyday lives.”

Jason Redman never expected to find himself at a fashion show. Redman was a U.S. Navy SEAL who suffered injury to his face and body when he was struck by machine gun fire during a special operative mission in Iraq. He received the Inspirational Achievement Award for the clothing company he founded, Wounded Wear.

“People underestimate the power of clothing, the power of wanting to feel good and look like everybody else around us. And that’s what this organization does. So to be here, to be an awardee, to be a part of it, it’s pretty awesome.”



# Autism Blood Test May Be Available This Year

By: Judy Newman

From: Wisconsin State Journal/TNS — September 7, 2018

MADISON, Wis.—A company that says its findings will “revolutionize” the way autism spectrum disorder is diagnosed and treated is getting a boost from a scientific publication.

Research conducted by Madison-based NeuroPointDX in collaboration with the MIND Institute at the University of California, Davis shows subtle differences in blood can identify some children as young as 18 months with autism spectrum disorder.

The findings were published Thursday in a peer-reviewed scientific journal, *Biological Psychiatry*, for the first time, and a blood test for autism is expected to be available before the end of the year, NeuroPointDX CEO Elizabeth Donley said.

In the largest study that’s been conducted on the metabolism of children with autism, NeuroPointDX discovered three panels of biomarkers that are shared by one of every six children diagnosed with autism who participated in the study.

NeuroPointDX’s Children’s Autism Metabolome Project, or CAMP, studied blood tests from 1,100 children between 18 months old and 4 years old at eight locations around the U.S. over more than three years.

It showed that when plasma from 516 children with autism spectrum disorder was compared with that of 164 children of similar ages without the disorder, abnormalities in three amino acid groups were identified in 16.7 percent of the children with autism.

New Jersey Council on  
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NJCDD



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families, as well as new ways to  
participate

The three biomarker panels were detected with a high level of accuracy. “If the child is in one of the metabolic subtypes, we will be able to identify it in 96.3 percent of the cases,” Donley said.

She said the results mean that an analysis of biomarkers “will let us diagnose kids as young as 18 months and to give insight into what is different in their metabolism.” Current tests, based on behavior and developmental milestones, are not conducted until children are at least 2 years old, she said.

Donley said having the results published “demonstrates the strength of the research and its uniqueness. ... It’s a validation of all of the work that we’ve done and the richness of the CAMP study design.”

## Blood Test for Autism

Donley said NeuroPointDX plans to make a blood test available by the end of 2018 to screen for the three biomarker panels. The test, to be drawn first thing in the morning, did not need approval from

the Food and Drug Administration but instead will be handled by state-regulated clinical laboratories. It’s already been approved for use in 45 states, she said.

But it’s just the beginning. The three biomarker panels described in the journal article are among 12 biological subtypes of autism the CAMP study has identified. Donley has said the markers, showing differences in the way some children’s bodies process certain amino acids, account for about 30 percent of children with autism.

“It is unlikely that a single marker will detect all autism,” said David Amaral, of the MIND Institute, lead author of the journal article. “This paper demonstrates that alterations in metabolic profiles can detect sizable subsets of individuals with autism.”

Donley said over the next few years, researchers hope to identify the metabolic differences that account for as much as 70 percent of those on the autism spectrum and to learn enough about the



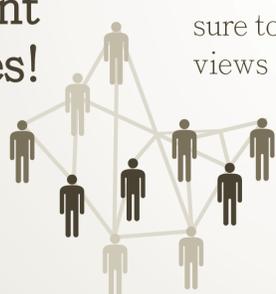
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biology involved to prescribe a specific treatment for each individual. Changes in diet, dietary supplements or medications could prove useful, she said.

“We know a patient who has diabetes can be treated with managed diet and insulin, if necessary. Here, we are looking at biomarkers in blood—amino acids rather than sugars. ... They come from what we eat,” Donley said.

Geraldine Dawson, director of the Duke Center for Autism and Brain Development at Duke University, said a reliable, early biological marker is a critical need in the autism field. “The sooner families can receive information that their child is at high risk for autism, the sooner they

can begin effective behavioral or other therapies,” said Dawson, who was not involved in the study.

As for how to decide which 18-month-olds should be tested for autism, Donley cited a Centers for Disease Control and Prevention study that showed about 17 percent of children have developmental delays. “That is the population of patients that we would want to reach first,” she said.

Donley said she thinks the study will provide data for autism research for years to come. “With this CAMP study and our very highly precise metabolomics platform, it’s a whole new way of diagnosing and treating autism,” she said. **P&F**

## UPCOMING EVENTS

### NJCDD COUNCIL MEETING

**Thursday, October 25, 2018**  
9:30am – 2:00pm

**Hilton Garden Inn Hamilton**  
800 Route 130  
Hamilton, NJ 08690

All Council meetings are open  
to the public—

If accommodations are required, please  
contact the NJCDD offices at 609-292-3745

### NORTHERN REGION DEVELOPMENTAL DISABILITIES EDUCATION DAY

**Saturday, October 27, 2018**  
10:00am to 3:00pm

**Liquid Church**  
299 Webro Road  
Parsippany, NJ 07054

Self-Advocates and Families  
welcomed to attend

To RSVP: [Kyoko.coco@njcdd.org](mailto:Kyoko.coco@njcdd.org)

## 2018 MIDTERM ELECTION DAY

**Tuesday, November 6, 2018**

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**[www.njelections.org/voting-information.html](http://www.njelections.org/voting-information.html)**

# New Jersey Introduces its First Ombudsman for People with Developmental Disabilities

By Jonathan Jaffe



Paul Aronsohn

There is no question that New Jersey's first-ever ombudsman for people with intellectual and/or developmental disabilities can relate to families and the myriad of issues they face.

Paul Aronsohn, who started in this new role on April 16, often shares the story of his sister, Patti, who passed away last spring at age 55, after living many years with a severe, degenerative disability.

Aronsohn knows all about the enormous cost of care, and the critical role of Medicaid and Medicare as life-saving safety nets. He can tell you about the struggles of finding qualified Direct Service Professionals for advanced care that stretches 24 hours a day, 365 days a year. And he can tell you about the importance of family, as his mother, Margot, at age 81, took care of Patti to the end of their lives.

In early June 2017, both died, within three days of one another.

“Governor Murphy appointed me as ombudsman because I can relate from a family perspective,” said Aronsohn, the former mayor of Ridgewood and a former Congressional candidate for the 5th District. “I can share a perspective from this population, understanding the challenges they face, and pushing the envelope. Often, families are worried to raise their voices, concerned they would lose what little they have. I am here to help.”

Aronsohn has an enormous task, but currently does not have any staff. He spends his days defining the job of an ombudsmen, meeting with lawmakers and decision makers around the state. He also invests plenty of his time for one-on-one contact with people with disabilities and their families, serving as a link to state resources.

It seems like the type of job that would require the services of an entire bustling state department. After all, there are at least 25,000 adults in the state who receive services from the state Division of Developmental Disabilities (DDD).

But Aronsohn is treading in new waters, eager to convince the powers-that-be that his services are of immense benefit to a population of residents who often do not have a voice at the table where decisions are made.

“Right now, the trick is to be anywhere and everywhere,” he said. “People need to know I exist.”

The future would certainly require more staff and a bigger budget. But, at the moment, Aronsohn is focused on meeting the many requirements of his position, as stipulated in legislation known as A. 3824, which Gov. Chris Christie signed into law Jan. 8 as one of his final acts as governor.

Many agree: Aronsohn seems ideal for the position. A politically-connected Democrat, serving a new Democratic governor, he is involved in a laundry list of organizations serving people with disabilities. He notes that when he was first sworn in to the Ridgewood Village Council on July 1, 2008, he propelled disability rights to a top issue in town.

Aronsohn is quick to refer you to his LinkedIn profile, which lists a number of organizations he is involved with, including the Adler Aphasia Center, the Bergen County Disability Services Advisory Board and the Ridgewood Community Access Network.

With a background in public relations, he has also been regularly published about disability issues, with articles with such titles as “Celebrating a Milestone for Disability Rights”, “For Parents of Disabled Children, Hope for the New Year” and “Compassion Needed in the White House.”

Dan Keating, executive director of The Alliance

for the Betterment of Citizens with Disabilities (ABCD), welcomes the new ombudsmen, noting Aronsohn can help build connections between the state, care providers, families and individuals.

“We are all in this together and we all need to figure out a way to work together,” Keating said. “When problems arise, families can certainly have an issue with the state. Having an objective person at the table is important. An ombudsmen will try to come to an agreement, settlement or resolution to what concerns people.”

Keating hopes that Aronsohn can focus on the chronic shortage of Direct Service Professionals in the state, keeping the issue in front of the governor and state Legislature.

*With a background in public relations, Aronsohn has also been regularly published about disability issues, with articles with such titles as “Celebrating a Milestone for Disability Rights”, “For Parents of Disabled Children, Hope for the New Year” and “Compassion Needed in the White House.”*



*Paul Aronsohn meets Quest participant, Linda Videtti (seated).*



*Quest participant, Gina Kreiger enjoys a moment with Paul Aronsohn.*

“Yes, the state has needs and financial problems,” he said. “But there needs to be a solution to our workforce crisis. It can’t be left unaddressed.”

Tom Baffuto, executive director of The ARC of New Jersey, said families need accurate information and assistance when it comes to processes and services.

“We look forward to helping the ombudsman toward a common goal of improving the system,” Baffuto said. “This includes addressing the critical issues of Direct Support Professional wages and increasing the availability of behavioral and medical care in all areas of the state.”

Aronsohn noted it is important that his office is independent of other state agencies, placed “in, but not of” the state Department of the Treasury. Even though he is a gubernatorial appointee and receives his paycheck from the state, Aronsohn considers himself free to focus on advocating for families, interacting with various state departments, no matter the issue.

“It is going to take some time to get the structure of the office right,” he said. “We don’t want to duplicate what is being done by the state or the New Jersey Council on Developmental Disabilities (NJCDD). I am taking some time to interact with individuals and families to help me think about what this will look like and what role I will play.”

It is a job with a macro focus, studying systems, developing long-range plans and holding policy discussions on a statewide level. And there is also the micro focus, the individual meetings with people who need help. As of late August, Aronsohn said, he has already worked with about 60 families.

One of those people he has met is Andrea Nixon of East Brunswick, who has had issues with the DDD regarding care for her 21-year-old son, who has autism.

“The state has pulled some fast ones about taking services away from him,” she said. “The ombudsmen was able to speak to people within DDD who have the ability to do something, rather than the minions who send you on wild goose chases. Paul didn’t know me from a can of paint, but he was one person who was willing to help me. He was actually listening to me. He was actually taking notes. And he actually called me back.”

Allison Marcilla, a social worker at Valley Hospital’s Center for Child Development, has a daughter, Jessica, with a rare developmental disability. The 17-year-old teen was placed in residential facilities for five years, before Marcilla pulled her out in 2016 for three months, and then permanently last November.

Jessica has been in a residential program in New Hampshire since July, where she is thriving. Marcilla handled the placement, noting the



*Paul Aronsohn meets with Carrie Hennessy (standing), and Maddy Blakeslee (seated) at Quest Autism in Midland Park.*



*Carrie Hennessy, and Maddy Blakeslee with Paul Aronsohn at Quest.*

state was not offering alternatives that addressed Jessica’s complex needs.

“As a social worker, I know the system better than anyone,” said Marcilla, who contacted Aronsohn when he was first appointed. “Families need help to navigate the system and that is why an ombudsman is so important. We need a voice for the families. The ombudsman is there to advocate for our children’s needs.”

Under the legislation, the ombudsman has specific tasks:

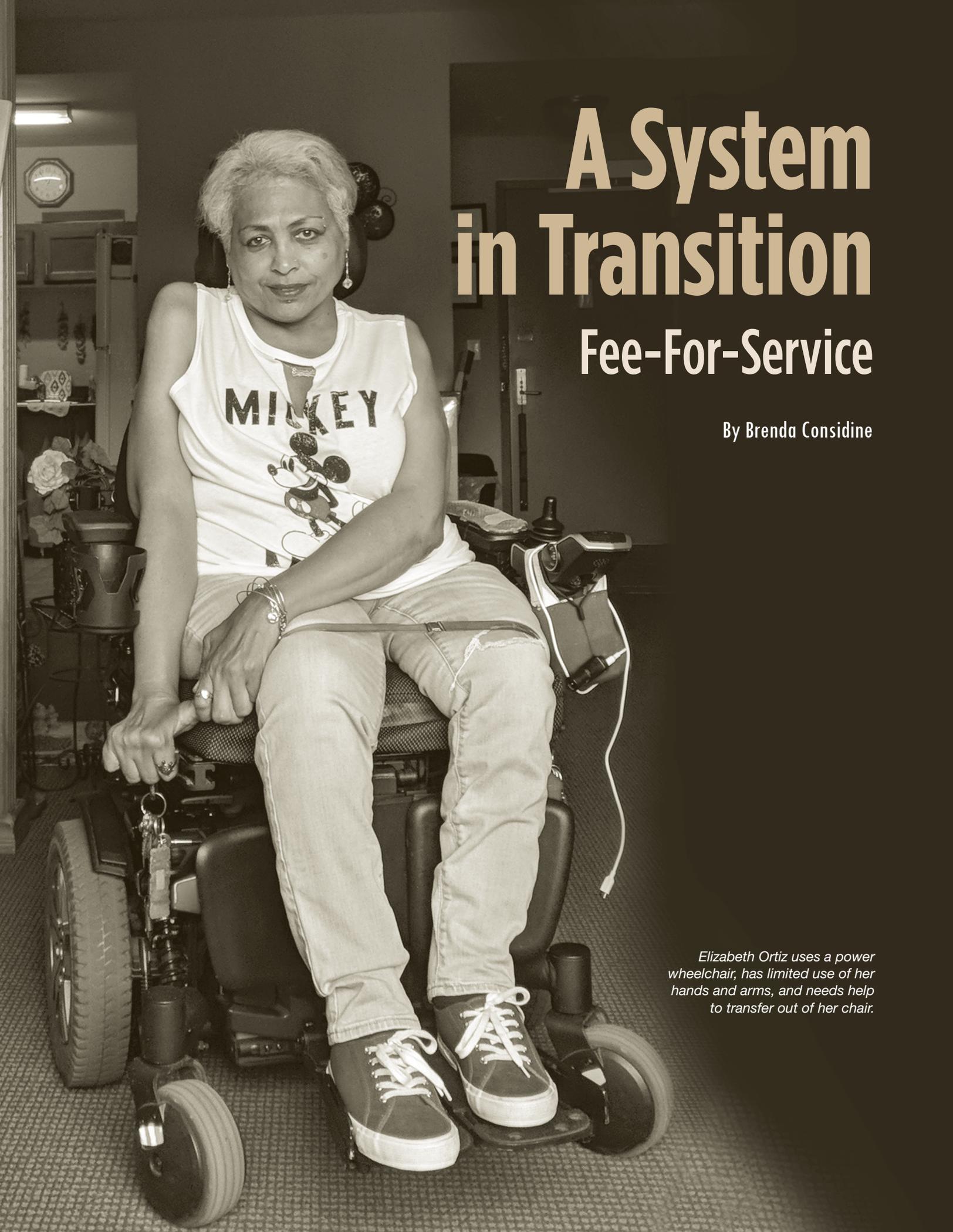
1. Serving as a source of information for people with developmental disabilities;
2. Coordinating with the NJCDD to provide information and support on obtaining state services;
3. Providing help for people with developmental disabilities to resolve disagreements with state agencies;
4. Working with service recipients, families and the departments to facilitate the provision of services and supports;
5. Identifying common concerns and making recommendations to the state; and
6. Assisting the Division of Children’s System of Care and the Division of Developmental Disabilities to create public information programs

Aronsohn works independently, often out of his car, but is required to write activity reports for the state Department of Human Services and the state Department of Children and Families, as well as the governor and state Legislature.

“Paul has been a long-time advocate for individuals with intellectual and developmental disabilities and their families, and we welcome his appointment to the Ombudsman role where he will continue this important work,” said Department of Human Services Commissioner Carole Johnson. “The Department is excited to have a strong partner in our efforts to improve the information and resources available to support individuals with intellectual and developmental disabilities.”

Department of Children and Families Commissioner Christine Norbut Beyer agreed, adding residents with developmental and intellectual disabilities are well-served with advocates at the table.

In announcing Aronsohn’s hire, Gov. Phil Murphy said: “New Jersey remains committed to enhancing opportunities for individuals with disabilities. With Paul’s leadership, I am confident that New Jersey will continue to protect the rights of people with disabilities and ensure every person has access to the American Dream.” **P&F**



# A System in Transition

## Fee-For-Service

By Brenda Considine

*Elizabeth Ortiz uses a power wheelchair, has limited use of her hands and arms, and needs help to transfer out of her chair.*

## Elizabeth Ortiz has a hard time going to sleep.

Ortiz lives alone in an apartment in Union City. She uses a power wheelchair, has limited use of her hands and arms and needs help to transfer out of her chair. Since the state's fee-for-service system has gone into place, she has less funding and as a result, has had to cut overnight support staff.

"I needed to use the bathroom at night, but there is no one here to help me," she said. "What am I supposed to do?"

"I am alone all night. It only takes one problem. I cannot cook, or eat, or use the bathroom without help. Cuts here, cuts there. It makes me feel like my life is not worth much," she added. "I have made adjustments, but I am advocating for more hours."

Ortiz is not alone. Families, consumers, providers, support coordinators and advocates are adjusting to the changes brought about by New Jersey Division of Developmental Disabilities' (DDD) new "fee-for-service" system. As the agency shifts from a contract-based system of service reimbursement to a Medicaid-based, fee-for-service reimbursement system, DDD is working to create more equity in funding, and greater consistency in service provision.

Fee-for-service has the potential to dramatically increase the number of people served by DDD, because Medicaid will match each dollar of state spending, as long as Medicaid rules are followed. The reform effort in New Jersey reflects an evolution in how the federal Medicaid program is used to fund community-based

services for people with disabilities, thanks in part to federal waivers that have given states flexibility in how they spend this mix of federal and state money.

### Impact on Families and Consumers

DDD is working hard to give consumers and their families more freedom and choice. Funding is highly individualized, based on a person's needs. Once a budget is established, the person and his/her family can select the services and the provider they want, and can decide when and where they want supports.

It sounds great, and for 25-year-old Evan Davidson, a resident of Gloucester County, it is. His mother, Phyllis Davidson, said the fee-for-service system has been "a God-send" for her son, whom she describes as "100 percent dependent." He uses a wheelchair, has a feeding tube, uses diapers, and does not use words to communicate. He receives services through the Medicaid Community Care

Program (CCP), formerly the Community Care Waiver (CCW), and now has enough funding to pay for more than 40 hours of in-home care and 30 hours of a day program each week.

Evan also is part of self-directed services, an option Davidson loves.

"We are able to pay his workers more than an agency can, because all of the money goes directly to them. I personally don't care for agencies," she said.

When she ran her most recent ad for in-home help, Davidson got 50 resumes, and found a perfect person—an RN with 15 years experience. She completes the online time sheets using an iPad.

"Honestly, I think this system is so much better," she said. "My only complaint is that we had to wait so long to get this help."

*DDD is working to create more equity in funding, and greater consistency in service provision.*

Not all families are so happy with the change.

Like Elizabeth Ortiz, Matthew Weiss has lost services. Matthew attends a day program for adults with autism 9 miles from his home in Passaic County. Like Evan Davidson, Matthew has an overall budget of more than \$300,000 a year. But he cannot access his budget to meet his needs.

This spring, Matthew's day program announced that they could no longer provide transportation to people outside the catchment area. After three months of working with a support coordinator, filling out paperwork—and doing the driving herself—Matthew's mother, Josie Weiss, has an answer but it is far from ideal. Matthew's budget for 'goods and services' can be used to fund transportation, but only one way.

"One way transportation for the year is \$7,200, which is half of his budget for "goods and services, so I am picking him up every day so that he can use the rest of the money for other things," Weiss said.

"DDD denied his Brain Balance program and his gym membership. I tried to get the gym approved, but that has been declined again. I have no idea why," said Weiss.

Lisa Ford, Director of The Arc of New Jersey's Family Advocacy Institute said her organization is hearing from families who are no longer able to get certain program through "goods and services."

"There are some popular college programs and gym memberships that are no longer funded under fee-for-service. It is unfortunate, but for some, the switch has actually opened doors. One family found out that the dance school where their daughter was taking classes was approved, and now that service can be funded," she concluded.

That is not the case for Jean Delgado's 31-year-old son, Richard. He learned that he can no longer be funded for his personal trainer and gym membership. In addition, the dance class and sign

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*Dr. Bruce Ettinger, Executive Director of Spectrum360, joins Kim Rushmore, Program Director of Independence360 in congratulating Willem Trampota for advocating for more shifts at his job as a skate guard at Codey Arena. Willem also has a second job near his home, where he works as a dishwasher three days a week.*



*Matthew Weiss has lost services. Matthew attends a day program for adults with autism 9 miles from his home in Passaic County. Like Evan Davidson, Matthew has an overall budget of more than \$300,000 a year. But he cannot access his budget to meet his needs.*



*Matthew Weiss is the son of Josie Weiss.*

language class he attended for years were casualties of the fee-for services system.

“They suggested that Richard go for Occupational Therapy instead of the gym. But he needs fitness, not short term therapy,” said Delgado. “Our kids tend to be sedentary. Without the personal training, he is already losing strength and body mass and has gained weight.”

Evelyn Dudzic, a parent who is also a provider, had been running the dance program and sign language class in rural Sussex County since 2008 as a DDD-approved vendor, but when the new fee-for-service system started, she found she could not cover her costs, so she was forced to close the program.

“The fee-for-service rates did not pay enough for me to pay my staff and cover the insurance. The funding is ridiculous,” Dudzic said. “This is a part of the state where there are not many services to begin with.”

Weiss believes there needs to be greater access to CCP and easier resolution to transportation issues. She also thinks that there needs to be more transparency in the approval process for services under “goods and services”.

“I just want to know who decides what gets funded and what does not? Who is ‘Oz’ behind the curtain?” she asked.

## **Impact on Providers**

For providers, changes resulting from the fee-for-service model are seismic. Instead of an annual contract with predictable monthly funding from DDD, provider agencies will bill Medicaid for specific services they provide to each individual after the service is provided, more like a doctor’s office. Each service has a fee or rate based on the person’s funding tier.

Currently DDD contracts with roughly 450 community-based organizations that provide day programs, employment supports and residential services, but not all agencies are in the fee-for-service system yet.

“We thought we would be there by now, but we are still in flux, said Valerie Sellers, Executive Director of the New Jersey Association of Community Providers, a trade association of agencies that provide community-based day and residential services to people with I/DD. “Most agencies have a foot in both worlds (contract funding and fee-for-services) until we reach full conversion,” she said.

The new system has some unanticipated problems. Any time a person is absent from the program, the provider cannot be paid. In some residential programs, longer-term absences due to family vacation, medical conditions or any other

reason can put the person at risk of losing their placement.

“When someone is out of program for weeks or months it is hard for the provider to hold the bed open,” said Sellers. She advises families to ask questions upfront so they know if there are any consequences if they bring their son or daughter home for the weekend or on a family vacation, causing a prolonged or repeated absence from the program.

“Providers and families were hoping for more flexibility. Now, there is no defined income—providers are subject to billing and proper coding. Claims are sometimes rejected and there can be delays in payment,” she added.

While some residential providers are doing better financially, most day programs are struggling because the rates are insufficient to maintain the program model. This is a particular burden for smaller providers who are not sitting on

a large reserve and who may need to get a credit line just to cover payroll.

One of those providers is the Essex county-based Independence360 (I360), a program of Spectrum 360. The nonprofit opened its day program for adults with autism and related disabilities five years ago with 30 adults, and today serves more than 100. Last year, I360 raised \$600,000 to cover costs of renovation of rented space for the program.

“The funding system does not cover those costs,” said Dr. Bruce Ettinger, executive director. “There is no way to recoup interest or depreciation on a site. Next year, we expect to fundraise more than \$160,000 just to cover our costs.”

“We serve adults who need far more support than their budgets can afford. Even the higher tiers are not enough to get the staffing for their needs,” he said. “And when our adults are absent, we don’t get paid, even though our other costs are constant,” he said.

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*(L-R) Kim Rushmore, Program Director of Independence360, Lineu Portugal, Chef Theresa Erickson, Dr. Bruce Ettinger, Executive Director of Spectrum360, Julie Bassolino, Eric Perkins, Kendell Barnes, Willem Trampota, Cara Minor, Natalie Canosa.*



*The service system used to be one big blanket. Now it is a patchwork of funding sources, but they are not really stitched together yet.*

—Maria Fischer



*Maria Fischer is a parent of a child with disabilities, as well as an attorney at Hinkle, Fingles, Prior and Fischer*

## A Patchwork

Maria Fischer is both a parent and an attorney with Hinkle, Fingles, Prior and Fischer, a firm that specializes in disability law. She and other lawyers at the firm hear from families who are trying to make the new system work.

“We thought fee-for-service would give families more choice and put them in the driver’s seat because providers would have to compete for the funding. That part is true: Providers have stepped up to make their programs more attractive, but the problems now all boil down to budgets and approvals. The service

system used to be one big blanket. Now it is a patchwork of funding sources, but they are not really stitched together yet,” Fischer said.

Evelyn Dudzic, who is 75 and has been involved in the DDD system for many years, is not impressed.

“The younger parents have nothing to compare it to, so they think it’s ok. It’s not. I know what it used to be, and it was better,” she said.

In spite of these challenges, however, Phyllis Davidson has hope.

“This new system is not going away,” said Davidson. “The state has put a lot of energy into this and now there is no going back. I am happy about it because if Evan was not at home with me, he would be in a nursing home.”

“The money is there and there are so many options. Give it a chance.”

*Footnote: As P&F goes to press, DDD has initiated a mechanism to inform families and consumers about decisions regarding denial of funding for services paid through the ‘Goods and Services’ portion of the budget. This process now includes a letter explaining the denial, and a process for appeal and a fair hearing.*

To learn more about Policies and Procedures, go to:

[www.nj.gov/humanservices/ddd/documents/ccp-policymanual-may2018.pdf](http://www.nj.gov/humanservices/ddd/documents/ccp-policymanual-may2018.pdf) **P&F**

For Dr. Ettinger, the paperwork and reporting requirements are a huge burden.

“I have to pay for more hours for them just to fill out paperwork and we had to hire a new person in the business office to keep track of the billing. We even needed a Medicaid expert to help us develop a compliance manual – the level of bureaucracy really detracts from the program,” he concluded.

Like many others, Dr. Ettinger continues to grow his program out of a sense of moral imperative.

“We had a homecoming for our school alumni and were shocked to see how many had regressed—they lost skills and language because they were not in a program, or they were in the wrong program, or they got kicked out. And those who had jobs were isolated and lonely—that is why we started the program and why we will keep fighting,” said Dr. Ettinger,

## Role of Support Coordination

Support coordination agencies play a central role in the new system, helping families and individuals find and access services. These impartial, independent third-party coordinators are selected by families to help them navigate the system but Sellers says the training of support coordinators has been a challenge.

“We have a lot of support coordinators who are still learning their jobs,” Sellers said.

# Independent Living Options for Adults with Disabilities

By Maryann B. Hunsberger



Since 2017, the Division of Developmental Disabilities (DDD) has been making rental subsidies available to eligible individuals. These subsidies are being distributed in the form of housing vouchers through the Supportive Housing Connection (SHC).

Housing payments are no longer being paid through DDD contracts with provider agencies. Instead, they are being paid through the SHC, which is a partnership between the New Jersey Housing and Mortgage Finance Agency (HMFA) and the New Jersey Department of Human Services (DHS).

The goal of the SHC is to provide access to affordable housing for New Jersey residents with disabilities by combining DHS's rental subsidy resources into one location. This combined effort will help provide more independent living options for New Jersey residents with disabilities. This is possible since DDD has changed from a contract-based system to a Medicaid-based fee-for-service system.

The SHC will provide landlord outreach and training, rental and other housing assistance, unit referrals and inspections, as well as services to answer tenant questions. They also manage rental subsidy payments, calculate a tenant's rent amount, recertify tenant subsidies annually at the end of the lease terms, and ensure that units are safe and compliant with federal housing quality standards and national best practices.

DHS will provide policy direction for the SHC, refer qualified tenants, and provide funding for the processing of housing subsidies

through the SHC. Only DDD-eligible individuals can obtain a voucher. They must have current and active Medicaid, have a current NJ Comprehensive Assessment (NJ CAT) from DDD and have an assigned support coordinator.

Individuals enrolled on the Community Care Waiver (CCW) who are self-directing their services in an unlicensed residential setting, as well as individuals on the CCW waiting list who have been reached in the current fiscal year initiative, may qualify for vouchers. Consumers and their families can obtain more eligibility information from their current service provider.

## Consumer Benefits

Besides using vouchers for group homes and supported apartments, voucher holders can also use the vouchers when locating any type of housing with an independent owner. "The SHC provides increased flexibility for individuals who want to live on their own because the vouchers are portable and linked to the person, rather than a service provider. The tenant-based vouchers offer individuals the flexibility to move within New Jersey," said Courtney Davey, DDD's Housing Subsidy Program Supervisor.

Another big change for consumers will be the cost. Under the old system, individuals living in a DDD-funded group home or supervised apartment (or their representative payee) were required to pay 75 percent of the individual's monthly income to the state. Under the new system, once an individual's lease goes into effect, this will no longer be required. [A lease will be

used whether in a group home, supported apartment or an independently-owned unit.]

Instead, an individual will pay 30 percent of his or her income to the landlord toward the cost of rent. [In DDD-funded residential settings, the provider agency that owns or leases the home is the landlord, and the individual who lives in the home is the tenant.] The provider agency may also determine an additional portion of an individual's monthly income that must be paid toward other living expenses, such as food and utilities. The SHC pays the rest.

The SHC will assist individuals and families served in this program to establish these leases, which will protect their rights as tenants under New Jersey law. Individuals in residential settings, or their guardians, will be required to sign the lease, which includes information about the person's basic rights as a tenant.

The tenant contribution will be reviewed annually in the event of income changes. SHC staff will contact the individual, landlord, and provider about 120 days before the lease or residency agreement expires to recertify the tenant each year.

Consumers also benefit because SHC connects individuals served by DDD to a broader pool of housing opportunities through the New Jersey Housing Resource Center (NJHRC). Davey pointed out, "Families will benefit from having more opportunity to plan, since SHC subsidies offer families the benefit of choice in a variety of community settings."

Davey also emphasized that consumers will benefit from enhanced communication, since tenants will receive communication directly from the SHC regarding their subsidy, and tenants will be able to directly contact the SHC regarding unresolved housing issues. Consumers will also benefit from enhanced advocacy and conflict resolution with community landlords. "If the landlord is refusing to address a maintenance issue, the individual can alert the SHC. The SHC conducts emergency inspections and monitors the progress of a unit that fails inspection."

It is important to note that SHC vouchers will not affect any supportive services that the individual currently uses. There is no time limit on how long a person can use the SHC voucher. However,

people receiving an SHC voucher can also apply for other sources of vouchers. "Any person can apply for any other assistance when the applications are available to the general public," said Elena Gaines, supervisor of rental assistance operations at the NJ Department of Community Affairs (DCA), which houses SHC.

## How to Participate

To take advantage of these services, DDD-eligible individuals or their families should first contact their service provider to inform them of their interest in seeking DDD-funded housing.

The service provider will then notify SHC. The consumer or their family will then receive a welcome packet from SHC.

After receiving the welcome package, consumers have 90 days to find a residence. Each individual's service provider may assist them in locating a residential unit. If additional assistance is needed, consumers can browse the New Jersey Housing Resource Center at [www.njhrc.gov](http://www.njhrc.gov) or call the SHC at 1-844-216-6988 to find suitable housing.

Once housing has been identified, the SHC will inspect the unit to make sure it is safe and suitable for occupancy to ensure that participants live in safe, high-quality housing. Tenants should not sign a lease until after a unit has passed the inspection. When the consumer is informed that the unit has passed inspection, the SHC will perform an income review, and will collect the consumer's signed Tenant's Rental Subsidy Agreement, the lease, and all income documents.

The SHC will inform the consumer of the exact amount of their contribution to rent, as well as the subsidy amount, and will clear the individual to move into the unit.

The provider agency will work with the individual and the representative payee throughout the entire process to find housing and to provide updated income and rental paperwork.

Individuals will receive a letter in the mail showing the date their rental payment to the residential service provider will begin. If currently living in DDD-funded housing, the Contribution to Care payment to the state of New Jersey will end on that same date. **P&F**

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

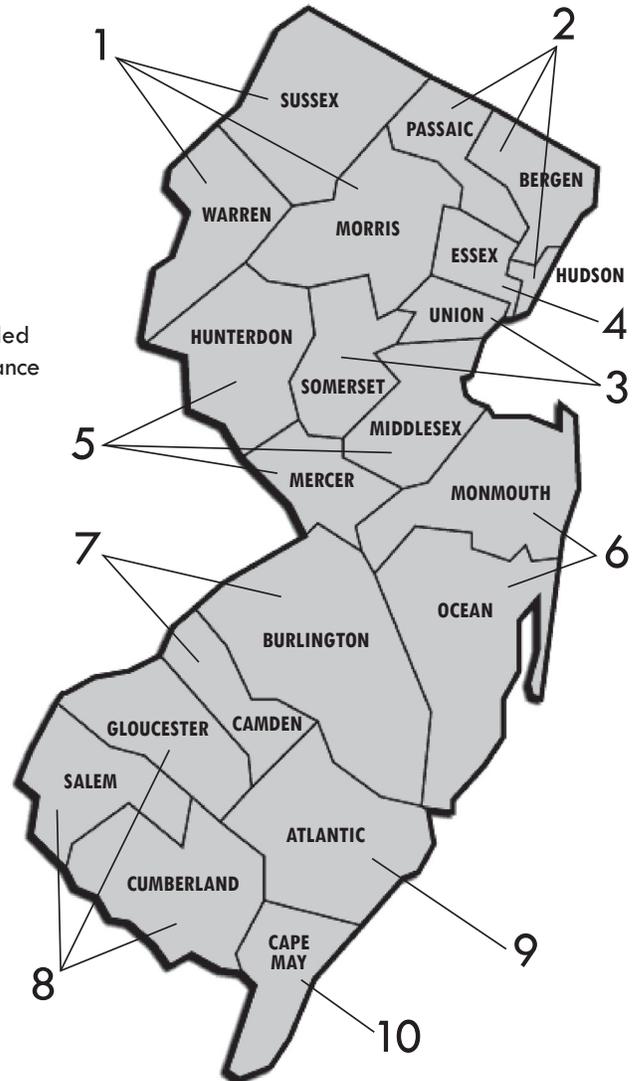
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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](mailto:kyoko.coco@njcdd.org)

Or visit our website at [www.njcdd.org](http://www.njcdd.org) and follow the link to Family Support & Facebook page at [www.facebook.com/NJFSPC](https://www.facebook.com/NJFSPC).

#### THE FAMILY SUPPORT ACT OF 1993

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

Visit the NJ Council on Developmental Disabilities' web site at: [www.njcd.org](http://www.njcd.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 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](mailto:RFSPC2@gmail.com)**  
**Co-Chairs: Frank Fiore, Fel Lim**

Meets the third Monday 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)**  
**Chair: 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)**  
**Chair: Paul Blaustein**

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

## 6 MONMOUTH, OCEAN

**RFSPC #6**  
**PO Box 76**  
**Lakewood, NJ 08701**  
**e-mail: [rfspc6-chair@excite.com](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 700**  
**Trenton, NJ 08625**  
**e-mail: [rfspc7@gmail.com](mailto:rfspc7@gmail.com)**  
**Co-Chairs: Laura Kelly, Kathy Freeman**

Meets the fourth Thursday of the month  
(Morning & Evening)  
Morning - 11:30 a.m. - 1:30 p.m.  
Cherry Hill Public Library; Main Floor  
1100 Kings Hgwy North  
Cherry Hill, NJ 08034  
Evening - 7:00 p.m. - 8:45 p.m.  
Bancroft School; Activity Center  
311 Walton Ave  
Mt. Laurel, NJ 08054

## 8 CUMBERLAND, SALEM, GLOUCESTER

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

Monthly teleconferences will be held  
in Jan - June 2018 in lieu of  
face-to-face meetings.  
For call-in information, email Chair

## 9 ATLANTIC

**RFSPC #9**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC9@yahoo.com](mailto: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](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

[SECOND REPRINT]

SENATE, No. 757

STATE OF NEW JERSEY

INTRODUCED MAY 7, 1992

By Senators DiFRANCESCO, INVERSO, Ewing, Cafiero,  
Cowan, Menendez, Feldman and Littell

1 AN ACT concerning family support<sup>2</sup>[,] and<sup>2</sup> supplementing Title  
2 30 of the Revised Statutes <sup>2</sup>[and making an appropriation]<sup>2</sup>.

3

4 BE IT ENACTED *by the Senate and General Assembly of the*  
5 *State of New Jersey:*

6 1. This act shall be known and may be cited as the "Family  
7 Support Act."

8 2. The Legislature finds and declares that:

9 a. It is in the best interest of the State of New Jersey to  
10 preserve, strengthen and maintain the family unit. All  
11 individuals, regardless of disability, have the right to belong to a  
12 family unit where enduring relationships can be fostered.

13 b. Families are the major providers of support, care, training  
14 and other services for their <sup>1</sup>[developmentally disabled]<sup>1</sup> family  
15 member <sup>1</sup>with a developmental disability<sup>1</sup> living at home.  
16 Consequently, families are continually searching for ways to  
17 support <sup>1</sup>[developmentally disabled]<sup>1</sup> family members <sup>1</sup>with  
18 developmental disabilities<sup>1</sup> in their homes instead of placing  
19 these individuals in a State or private institution.

20 c. Many families with a <sup>1</sup>[developmentally disabled]<sup>1</sup> family  
21 member <sup>1</sup>with a developmental disability<sup>1</sup> experience  
22 exceptionally high financial outlays and extraordinary physical  
23 and emotional challenges, isolation, stigmatization and daily  
24 stress. Supporting families in their effort to care for their  
25 <sup>1</sup>[developmentally disabled]<sup>1</sup> family member <sup>1</sup>with a  
26 developmental disability<sup>1</sup> at home is efficient, cost effective and  
27 humane; failure to provide needed supports can result in

# Celebrating 25 Years of the Family Support Act

By Brenda Considine

The opening sentence of the Family Support Act says it all:

*“The Legislature finds and declares that it is in the best interest of the State of New Jersey to preserve, strengthen and maintain the family unit. All individuals, regardless of disability, have the right to belong to a family unit where enduring relationships can be fostered.”*

The Act goes on to describe the role of families in providing care, and the tremendous costs—financial, physical, social, and emotional—that are incurred when raising a child with developmental disabilities.

Line 30 of the Act reads:

*...“To be effective, family supports must support the entire family, must be easily accessible, flexible, culturally sensitive and individualized...”*

And line 38 of the Act reads:

*“...A Statewide family support policy must acknowledge that families themselves are able to define their own needs and select their own services: family supports must be chosen by families, controlled by families and monitored by families.”*

The preamble language in that bill was very important, not just because of what it says, but because of how it got there: It was carefully crafted, not by pundits and policymakers, but by families and advocates.



When it was signed into law, the Family Support Act of 1993 marked a turning point in the history of disability policymaking in New Jersey. For the first time ever, decision-making was placed in the hands of families.

William Waldman, Commissioner of the Department of Human Services at the time, calls the Family Support Act “a watershed moment” in New Jersey history.

“The Act embodied everything that was happening in the system. We were just beginning to move from an institutional model to a more community-based, family-based, consumer-driven model. The bill was a turning point in the way it engaged families. It was historic and symbolic,” he recalled.

The goal was to provide the supports families need in order to help them stay together, preventing the premature need for residential services. The Act established a statewide system of family support services. It also established nine Regional Family Support Planning Councils (later restructured to ten), comprised of family members, to advise government on local needs. It expanded the array of supports and services families could access, and allowed them to use government funds to pay directly or indirectly for the services they needed, as well as to hire caregivers of their choosing. And, because advocates knew that even the best-intentioned legislation needed a watchdog, they insisted that the Act include a Statewide Family Support Coordinator within the New Jersey Council on Developmental Disabilities to oversee the ongoing implementation of the Act. It was a huge shift.

“We always said that family support was ‘whatever it takes’ to keep a family together. That was our tagline,” recalled Marilyn Kuna, an early leader in the fight for family support.

## A Long Road to Get There

The history of the Family Support Act is a study in grassroots organizing. A small group of dedicated family members and professionals organized a coalition to address the needs of families caring for a child with disabilities living at home.

Led by Sandra Jackson, the single mother of a daughter with significant disabilities, the group met for nearly two years. They studied model legislation from the handful of states that had passed a family support act, and learned all they could about best practice. Inspired by the pioneering work of Alan Bergman, a nationally recognized leader in the area of family support, the family support coalition strengthened and expanded its reach. They developed a list of principles and a singular goal: Family Support legislation.

Coalition leaders, with the support of statewide nonprofit agencies working in cooperation with the New Jersey Council on Developmental Disabilities, organized public hearings. They invited lawmakers, government leaders, and the press to hear directly from families. Over the course of a year, more than 300 families shared stories of the experiences they

faced raising a child with disabilities and expressed the examples of the need for flexible, family-driven support services.

At one of the hearings, one family said all they needed was a washer and a dryer. That was it. Another just wanted cash assistance to help pay for the adult sized diapers her teenaged son needed—the cost was keeping her other children from doing after-school soccer. Another family wanted to have a ramp put in at their home to get their son in and out the front door. It was not a lot.

Families not only *told* their stories, they *showed* their stories, bringing their sons and daughters with them to hearings, meetings, and rallies.

“Whenever I could, I brought (my son) William with me,” recalled Kuna. “I took him to the legislator’s office in Somerville, but the office was on the 2nd floor and there was no elevator. I had to ask the Senator to come downstairs to meet with us. He became a real advocate,” she said.

A group of parents met with a seasoned Senator from the shore area. Initially, he was not all that supportive—he thought family support amounted to state funded baby-sitting. But with their children in tow, these parents forged on. Five minutes into the meeting, the flag pole in the office had been knocked over, there was a child under the desk, and another child who, at the age of 9 or 10, needed to have his diapers changed—and there was no place to do that in a legislative office. Needless to say, the Senator signed on to the bill. After being introduced to their reality, the Senator really got it!

Organizers launched a petition drive calling for a system of family supports. More than 14,200 concerned citizens signed the petition—the old-fashioned paper kind on a clipboard. Page by page, the petitions were collected by The Arc of New Jersey, which played an important role in organizing and promoting the campaign.

The next step was to lay the groundwork for legislation. Advocates were careful to work with leaders in both houses who could champion the cause. Language for the bill was shared with Assemblywoman Maureen Ogden of Union County. She understood the issue and was ready to make it her cause.

### From The Family Support Act

The statewide system shall include, but not be limited to the following services: 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; voucher services and other services as identified by the family.

On May 4, 1992, a bright and breezy spring morning, Sandra Jackson stood on the state-house steps in Trenton before a crowd of more than 1,000 families. Governor Jim Florio declared the day “Family Support Awareness Day.” With reporters and camera crews present, she handed a foot-high stack of petitions over to Assemblywoman Ogden, with more than 14,200 signatures, calling on the state to establish a new system of family support. That day, she introduced the bill. Senate President Donald DiFrancesco introduced the Senate bill days later.

To build momentum, families across the state met with lawmakers to ask them to co-sponsor the bill; they came to Trenton in droves to share their stories.

“At these hearings, there is always a lot of noise, people coming and going, eating their lunch and moving around. But when I showed them a picture of William, and explained to this group of mostly men that I have to shave my adult son and change his diapers, the room went silent. I think I spent more time in Trenton that year than I did at home,” she said.

At one of the legislative hearings, there were so many families and kids in the room that the chairman asked for just one parent to speak for all of them. He assured the group that everyone planned to vote ‘yes’ on the bill, and he did not want to waste people’s time in a committee room. But the families hung in there. They agreed to keep their comments short, but did not agree to just go home, unheard. The hearing lasted for 3 hours. And they voted ‘yes’.

On March 29, Governor Florio signed The New Jersey Family Support Act of 1993, mandating a “coordinated system of ongoing public and private support services.”

### **Show Me the Money**

While the Family Support Act of 1993 called for a new system, it did not guarantee new funds. Initially, it called for \$100,000 to start the new system. Because of the energy and momentum behind the bill, the Department of Human Services also announced a \$3M initiative to address family support.



*Senate President Donald DiFrancesco and Assemblywoman Maureen Ogden accepting the petitions containing 14,000 signatures supporting family support from Sandi Jackson, President of the New Jersey Family Support Coalition. —Photo by E. Ozern*

The nonpartisan Office of Legislative Services (OLS) was unable to provide any fiscal analysis on the bill because the number of potentially eligible families was entirely unknown. Other than those on a waiting list for housing (about 3,100 people at the time) no one knew how many more families needed help.

*“...This would mean that each person would receive about \$29 in family support services annually, based on the available appropriation. As such services tend to stimulate demand, it is likely that significantly more families will apply for services.”*

In a blow to advocates, the Senate Budget Committee removed the \$100,000 appropriation in the bill. With all the hope—and hype—about the Family Support Act, there was no money to build the new system.

### **Making Up the Rules**

After a bill becomes law, the administrative branch of government is charged with writing rules and regulations. Typically, state bureaucrats do that, but in keeping with the spirit of the Family Support Act, this task too would be placed in the hands of families.

Gail Frizzell was one of the parents who stepped forward to help write the rules. She came to family support advocacy because of

her daughter Lauren, who was then only six years old.

“A staff person at SCARC invited me to a meeting where they were looking for families to help write the regulations. They needed someone from Sussex County and I was the only one, so I raised my hand. I was a complete newbie and I knew no one,” she recalled. “The family advisory group was so diverse—every ethnic group and culture, every age, every disability—it was kids through adults—we worked beautifully together.”

“We desperately wanted to get it right and have it be practical. We wanted it to be very flexible and meet everyone’s needs,” she said.

## The Next Chapter

While the Family Support Act is still the law of the land, in recent years, the concept of “whatever it takes” has been obscured, as supports have been cut back. The bill specifically allowed a cash option and a self-directed respite option, which are now at odds with Medicaid rules, which bars such services. In fact, in 2010, the entire \$7.5M cash subsidy program was eliminated and redirected to the waiting list. With only \$36.6M in state funds available for family support—less than any year in recent memory—some are saying that the lack of funding has left the promise of the Act unfulfilled.



*Colleen Fraser, former vice-chair of the New Jersey Council on Developmental Disabilities*

## The Roots of Self-Directed Services

One important story that is often overlooked in the history of the Family Support Act is the vital role of self-advocates. In fact, on the day the bill was headed for its first committee hearing, Colleen Fraser, a fiery advocate who served as Vice-Chair of the New Jersey Council on Developmental Disabilities, dug in her heels as she reiterated a major concern. With all the power in the hands of families, where was the self-direction and individualized supports for consumers?

That question—and its response—laid the groundwork for decades of efforts around self-directed services.

Line 42 of the Family Support Act: “Adults with disabilities should be afforded the opportunity to make decisions for themselves, live in typical homes and communities and exercise their full rights as citizens. Adults

with disabilities should have options for living separately from their families, but when this is not the case families should be provided the support they need.”

Colleen never held back and always spoke truth to power. She insisted that this language be added or she would pull her organization’s support for the bill. She saw power being handed to families and said, ‘Wait a minute—What about the individual? What if they don’t WANT to live at home? Shouldn’t they have the self-directed supports too?’ It was really one of the first public policy discussions about self-direction.

*Colleen was aboard Flight 93, which crashed in Shanksville Pennsylvania on September 11, 2001.*

Advocates have suggested that one way to keep New Jersey's family support system responsive and still benefiting from the waiver funds is to set aside "state only" funds in the family support system. This pot of money could be used to pay for those services not allowed under the waiver, such as cash subsidies.

"It is disappointing," said Frizzell. "We had such a different vision for it, but the system changed and services have been eliminated. Under the new system, the need for family support is treated like it is a temporary condition—families have to re-apply (to the Department of Children and Families) every three months. There is so little we can depend on. One of the purposes is to offer families a little bit of stability—and now that is gone."

Frizzell and Kuna still have the small gold starfish—a lapel pin—given to the early parent leaders who helped to write the regulations.

The starfish symbolizes the parable of the old man walking on the beach. He comes upon a young child surrounded by thousands of starfish washed up on the beach. While others simply walk by, overwhelmed by the scope of the problem, the child begins to pick up the starfish, one at a time, and toss them back into the sea. Puzzled, the older man asked, "Child, what are you doing?"

The child responded without looking up, "I'm trying to save these starfish."

The old man chuckled and asked, "There are thousands of starfish and only one of you. What difference can you make?"

Holding a starfish, the child turned to the man and gently tossed the starfish into the water, saying, "It will make a difference to that one!"

"And that is how it was," said Kuna. "We knew we could not help everyone, but the system sure helped those it touched."



Advocates for the Family Support Act gather at a rally in Trenton.  
—Photo by Rick Considine

Kuna, Frizzell and other early advocates—most of whom now have adult children nearing middle age—credit the Family Support Act as life-altering public policy.

"I have never had to consider an institution for William, and I owe that to the Family Support Act," said Kuna.

*Authors Note: I was privileged to have been involved in the early part of the movement that lead to the passage of the Family Support Act, and am deeply honored to have worked with the many leaders quoted in this story. I began my work in the field of disability policy and advocacy in 1984, a decade before I became a parent for the first time. At the time of the passage of the Act, my role was professional, not personal. Later, my own family benefitted from the Family Support System, with respite care and flexible supports for my son. I am deeply grateful for the visionary leaders who got the ball rolling! I have included some of my own recollections in this story as well. **P&F***



Jake's Place is a fully disability accessible playground in Camden County, NJ.

# Jake's Place

## A Playground that *ALL* Children Can Enjoy

By Jonathan Jaffe

It was on Oct. 21, 2007 that the family of Jacob Cummings-Nasto bid farewell to their 2-year-old boy, after his fourth open-heart surgery.

Jacob was born with half a heart, a rare birth defect.

In his short time here, Jacob often visited parks throughout South Jersey near his home in Pennsauken. The parks, filled with happy, laughing children, were this toddler's paradise for his physical therapy.

But it was impossible for Jacob to use the playground equipment because of his disabilities. But as much as he wanted to climb, slide and sway

—just like any other child his age—he still found joy in watching others enjoy the playground.

After Jacob died, his grief-stricken parents, Kate Cummings Nasto and Joseph Nasto, were eager to do something to honor his memory. There were thoughts of maybe a park bench or some sort of memorial.

But to truly honor Jacob, the family wanted to create a playground that any child—any child at all—could truly enjoy.

“We wanted to build something that Jake didn't have,” his mother explained. “We wanted a place for moms to take their children with disabilities.

We wanted them to have a place to go in which it didn't matter if the child happened to be disabled."

With grandparents who work in the non-profit sector, the family embarked on the creation of a non-profit organization, named "Build Jake's Place," convincing Camden County officials that such a project can be a reality. Then, there was the daunting task of fundraising upwards of \$725,000 to construct this "boundless" playground, relying on the generosity of individual donors.

"It was truly one penny at a time," Cummings Nasto said. "At times, it was almost as if we were going to go door to door, just asking for money."

The vision: such a park would have non-allergenic rubber, making it possible for any spirited child in a wheelchair to have a soft landing. There would be wide ramps, assisting devices and even a quiet area for children with autism. There would even be a swaying device for wheelchairs and aides, so children can get the feel of being on a traditional playground swing.

And that is exactly how the very first "Jake's Place" was constructed. It opened in September 2011 in Challenge Grove Park in Cherry Hill, an 18-acre county park on Bortons Mill Road, specializing in accessible amenities for people with disabilities. Build Jake's Place is proud to note the all-inclusive playground is considered one of the top facilities of its kind in the United States.

The park is also home to the Camden County Miracle League, with a ball field that accommodates players with disabilities. This "boundless field" is barrier-free, handicapped accessible, with a cushioned, synthetic, latex-free surface that accommodates wheelchairs and walking-assistance devices. The field has 50-foot base paths and a 125-foot run to deep center field.

Now, a second "Jake's Place" is being constructed in the Community Park on Hartford Road in Delran, a new facility that opened in April 2016. Besides "Jake's Place," to open next spring, the park features a Buddy Ball Field for children with disabilities. The first phase of the new "Jake's Place" will cost \$625,000, with a final expected price tag of more than \$700,000.

As the family eagerly awaits the delivery of playground equipment, they are also reflecting on how far they have gone over these past 10 years.



*On August 23, NJ Governor Phil Murphy signed legislation incentivizing counties across New Jersey to build inclusive playgrounds for children and adults with disabilities.*

All the hard work seemed to culminate on August 23 when the board members of the non-profit attended a bill signing with Gov. Phil Murphy in his conference room in Trenton. The bill, known as A. 2187, will forever be known as "Jake's Law."

The bill incentivizes counties across New Jersey to build inclusive playgrounds for children and adults with disabilities, finally giving thousands of New Jersey children, of every ability, a place to play.

"No child should lack access to playgrounds based on their physical abilities," Murphy said, at the bill signing. "I am proud that New Jersey is leading by example as an inclusive state through this act, ensuring our great state is a place that welcomes all nine million of us."

Jim Cummings, Jacob's grandfather and board member at Build Jake's Place, said the law places New Jersey at the forefront of a national movement of inclusivity. "It is hoped, within the foreseeable future, every play opportunity in the state will include every child of every ability," he said.

Jacob's mother, Cummings Nasto, was also quick to note that these all-inclusive parks are also meant to help parents with disabilities interact with their children. She points to a friend, a fellow mom, who happens to be deaf and blind. But she has twin boys, and she needs to go to a park where she can chase them down. There are also returning veterans with disabilities and others who are looking for a place they can enjoy with their kids, she said.

Under the legislation, counties that submit applications to build inclusive playgrounds similar to Jake's Place will be prioritized in Green Acre funding. The state Department of Community Affairs, in consultation with the state Department of Education, will create rules and regulations for design, installation, inspection and maintenance of these innovative playgrounds.

The rules and regulations will be implemented to exceed the requirements established by the federal Americans with Disabilities Act and ensure that these inclusive playgrounds are accessible for children with all physical and mental abilities.

Bill sponsors include Senators James Beach and Nilsa Cruz-Perez, as well as Assembly Majority Leader Louis Greenwald and Assembly members Pamela Lampitt and Gabriela Mosquera.

Learn more at [www.buildjakesplace.org](http://www.buildjakesplace.org) **P&F**



*The park has non-allergic rubber, wide ramps, assisting devices, and even a quiet area for children with sensory impairments.*

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# New White Paper Sheds Light on Challenges and Opportunities for Managed Long-Term Care

By Robert Titus, NJCDD Public Policy Coordinator

On June 28, 2018, The American Network of Community Options and Resources (ANCOR) published a new white paper, *Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities*.

According to the press release:

“Based on significant input from ANCOR members and other stakeholders, this new resource offers one of the most detailed examinations of the impact of Managed Long-Term Services and Supports (MLTSS) programs on individuals with intellectual and developmental disabilities (I/DD).”

While the growth of MLTSS is well-documented, ANCOR crafted this resource because of the scarcity of efforts focused on the MLTSS experience for people with I/DD. As CEO Barbara Merrill explains, “We knew there was a sense of urgency to issue much needed peer-reviewed research about this emerging landscape, and we are proud to reveal these important findings.”

She continues, “ANCOR’s findings build on the work of others who have probed the MLTSS environment, including recent reports from MACPAC—a report to which ANCOR contributed its input—and the MLTSS Institute. Specifically, the report broadens the base of knowledge on MLTSS by accounting for the experience of I/DD service providers and the state associations that represent them...”

The publication identifies many implications for New Jersey and other states. As the White Paper notes, New Jersey is one of twenty states that have voluntary or varied enrollment in Medicaid Managed Care (MMC) programs – most contract with Managed Care Organizations (MCOs) or Accountable Care Organizations (ACOs) to operate those programs. So far New Jersey has excluded people with I/DD from

MLTSS, so the experiences of other states that have included them should be of great concern to policymakers here in our state.

There are just a few states that have fully embraced MMC for people with I/DD, for the following reasons:

- Lack of potential cost savings in MLTSS-I/DD
- Limited MCO experience serving people with I/DD in MLTSS
- Limited state experience to set MLTSS-I/DD managed care rates
- Need for meaningful quality measures
- Lack of managed care experience among I/DD providers
- Unique role of I/DD case management and supports coordination
- Strong advocacy networks and relationships

As the report indicates, in a cautionary comment:

“...the most crucial aspect of MLTSS-I/DD program and implementation relates back to the state’s goals and reasons for moving services to managed care. Recent experiences of states demonstrate that focus primarily on cost savings, especially in the short-term, is unlikely to result in success, and may drive reductions in quality and/or service cuts that harm I/DD beneficiaries.”

Moreover, because Medicaid underfunds the majority of I/DD services (especially HCBS), providers must compensate for below-cost reimbursement (or more likely, rates) with fundraising contributions and developmental activities. “Direct support labor comprises the vast majority of Medicaid HCBS expenditures for people with I/DD, with approximately 1.3 million direct support professionals (DSPs) supporting people with I/DD enrolled in state agency services. Typical wages for DSPs are near the minimum wage; the average DSP wage is \$10.72/hour.” There is likely little or no cost savings possible.

There are other reasons to proceed with care:

- “I/DD stakeholders fear a return to a ‘medical model’ of services if measurement of quality of care relies primarily upon clinical outcomes and does not incorporate a broader definition of quality.” The definition widely varies as is expected.
- “Case management and supports coordination (sometimes referred to as service coordination, care management, or care coordination) for people with I/DD is often a much more significant and involved role than with other populations.” When MCOs become the responsible party for case management, disruption of trusted relationships can occur and “change the nature and function of supports coordination.”
- There is a strong existing advocacy network for people with I/DD, based upon the achievement of hard-fought funding and services over many years. “People with I/DD, families and providers are often deeply personally and emotionally involved, and are frequently skeptical of managed care, especially when the planned transition is focused upon cost savings.” This skepticism is backed up by a lack of evidence that MLTSS programs have resulted in improvements in I/DD long-term services in both cost-savings or quality of care.
- States, on the other hand, that “...focused on using managed care to address waiting lists, improve quality, address program goals and/or leverage the power of MCOs...toward truly integrated services...” have experienced much better results. Wisconsin has utilized MLTSS with the “explicit goals of ending the waiting list, improving access and choice, increasing quality and achieving cost efficiencies,” (as opposed to cost savings). The waiting list is expected to be eliminated by 2021. The Employment and Community-First (ECF) CHOICES program in Tennessee has successfully promoted integrated services in the community and is open to those on its waiting list for waiver services.

The White Paper made these references to New Jersey:

“New Jersey’s I/DD system has been evolving gradually toward a MLTSS structure

consistent with other populations already in MLTSS. One of the dynamics forcing the gradual evolution is the historic payment mechanisms the state has used to pay providers of services in their Community Care Waiver, the comprehensive I/DD HCBS waiver. In 2017, the state began converting their I/DD payment system to fee-for-service, a necessary step before the state could move to MLTSS because under the old payment process, the state collected very little data about utilization that would be needed to set capitation rates. According to stakeholders, transition to MLTSS is likely on the horizon, but there has been no proposed timeline issued by the state.”

The recommendations of the report are summed up in its ending statement:

**“...states’ experiences show that the decision to employ managed care for people with I/DD should not be made hastily or with the expectation of quick fixes or immediate cost savings.**

Examples from states implementing MLTSS for people with I/DD show that successful programs are most likely to result from careful planning, significant and ongoing engagement with stakeholders, and a clear policy vision intended to advance the goals of integrated, quality home and community-based services.”

The link to the White Paper is:

[http://ancor.org/sites/default/files/ancor\\_mltss\\_report\\_-\\_final.pdf](http://ancor.org/sites/default/files/ancor_mltss_report_-_final.pdf)

The American Network of Community Options and Resources (ANCOR) is a national trade organization for disability service providers, representing over 1,400 private providers of disability community services for people with intellectual and developmental disabilities and 55 state provider associations. Collectively, ANCOR members support over a million individuals with disabilities with a workforce that’s half a million strong. ANCOR’s mission is to advance the ability of its members in supporting people with intellectual and developmental disabilities to fully participate in their communities. [www.ancor.com](http://www.ancor.com)

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