

# Peoples & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 1, 2020

## DDD Fee-for-Service Self-Directed Models

*Self-directed home and community-based services offer increased control and choice.*

*Carrie Lerner and her music teacher Jim Gaven during a music lesson*





# Accessing Developmental Disability Services in New Jersey

## A Resource Guide for Individuals and Their Families.



The purpose of this guide is to provide basic information regarding how a person with a disability can access eligibility and intake for government-funded services.

Access the guide at  
<http://www.shanj.org/housing-hub/resource-guide>



Supportive Housing Association of NJ • [www.shanj.org](http://www.shanj.org)

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New Jersey Partners in Policymaking is an 8-month leadership development and advocacy education program for adults with developmental disabilities (over age 18) and family members. The goal of this program is to prepare the next generation of disability advocates to work toward meaningful change in New Jersey. This story highlights the experiences of a few of the program's graduates.

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Photo by Rebecca Shavulsky

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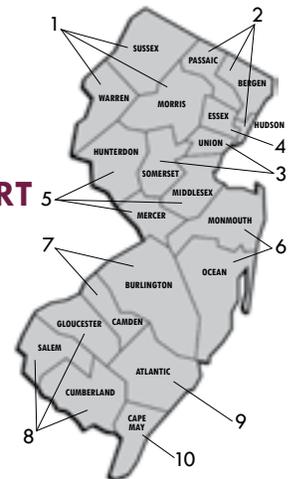
Beginning in early 2020, many families will find an easier, more streamlined process when applying for services through the Division of Developmental Disabilities (DDD) when their son or daughter turns 21. While they still have to fill out paperwork, they will no longer have to submit documentation to prove that their son or daughter has a developmental disability.



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## Reflecting on My First Year With The Council

It's already been more than one year since I took the helm of NJCDD. With so many goals, I feel like we barely scratched the surface of what we need to accomplish.

Although, I am proud to say we've made progress on pushing forward some very critical issues facing individuals with intellectual/developmental disabilities and their families. Because of your efforts, we've shed the light on the need for safer schools for people with disabilities. We continue our work at gaining bi-partisan support for some very important pending legislation. I'm confident we will continue to gain traction during the coming year, while gaining additional political support.

Disaster management succeeds only when everyone comes together to address the diverse needs of all citizens. Sixty-one million people have disabilities and countless others have access and functional needs. We must make sure that all people with disabilities are not forgotten when disasters strike.

Your admirable efforts supporting thousands of direct service professionals (DSPs) led to a \$40m funding increase in FY20 (federal and state funds). But, that is not enough. We must continue our efforts to bridge the ever-widening gap in pay between our valued DSPs, and those with much less demanding jobs.

Thanks to the commitment of staff members, self-advocates, and dozens of actively-involved family members in our Regional Family Support Planning Councils, we continue to provide much needed support for the families of individuals with disabilities across the state. Committed and vocal family members continue to represent a valuable link in the chain of our efforts to secure quality supports and services for individuals with intellectual and developmental disabilities and their families.

We're also well-positioned to galvanize our public policy efforts across our vast network as we set our sights on encouraging a disability caucus of key legislators. Our work in engaging our youth continues to help prepare the next generation of advocates.

The NJCDD awarded three new contracts focusing on housing, transportation and employment; what I often refer to as the 'trio' of services needed for individuals with I/DD to live successfully in their communities. We have also awarded a number of Community Innovation Projects to create innovative and sustainable programs across the state.



I continue to serve on the New Jersey Independent DD Fee-For-Service Oversight Board. The Board released its first report in September. Valuable input from listening sessions will be used in the next report.

All of the NJCDD position statements have been updated. Our updated statements on education and employment will be highlighted in this issue. As you know, these statements help set the stage for our work in supporting and advocating for individuals with intellectual and developmental disabilities and their families.

Sadly, this year has been marked by some personal and professional losses. Joe Amoroso, the former director of the New Jersey Division of Disability Services, passed away in September. Joe was a tireless advocate for the rights of people with disabilities.

I was deeply saddened by the loss of Daniel Keating, executive director of the Alliance for the Betterment of Citizens with Disabilities (ABCD). Dan was not only a powerful advocate who dedicated his life to improving the lives of others. He was a kind and compassionate leader who left an indelible mark on the hearts and minds of countless people including me.

Dan was very instrumental in helping to form the Developmental Disabilities Advocacy Network (DDAN). For me, the name “DDAN” has new meaning. We’ve continued to bolster our collective advocacy efforts through this initiative in his honor.

In this issue we feature Partners in Policymaking (PIP), while highlighting a few of the many people who have benefited from this program. We also provide some clarity on the complex, complicated, and often misunderstood self-directed service models.

And finally, we help shed some light on how to resolve disagreements in the special education system. It is vital that each student’s education is appropriately tailored to their needs. Our goal for this story is to help make resolving disputes with school districts a less daunting challenge.

I sincerely hope you enjoy this issue of People & Families.



*Mercedes Witowsky*  
Executive Director  
New Jersey Council on Developmental Disabilities



*Dan Keating addresses participants during the May 13 DSP Rally.*

# In Loving Memory of Daniel J. Keating III, Ph.D.

By Jeremy Einbinder

Daniel Keating, executive director of the Alliance for the Betterment of Citizens with Disabilities (ABCD) passed away on September 21, 2019 at the age of 70.

New Jersey Senate President Steve Sweeney issued the following statement:

“Individuals with disabilities lost a tireless advocate and pioneer this weekend. Dr. Keating spent a lifetime helping people with disabilities to achieve their potential and lead more fulfilling lives, and his contributions to our state will be felt for generations,” said Sweeney. “My heart is with his wife, Kathy; his daughter Karen; his son Philip and all of his family and loved ones. Thank you, Dan, for all your work, guidance and friendship over the years—rest in peace.”

A New Jersey native, Keating was born in East Orange. He was a member of The Brain Injury Association of Pennsylvania, and the Brain Injury Alliance of New Jersey. He had more than 30 years of experience advocating for people with disabilities.

Prior to joining ABCD as executive director, Dr. Keating was employed at Bancroft, a nonprofit focused on people with brain injuries, autism and intellectual disabilities. He held several positions during a twelve-year span with Bancroft. He was responsible for Family Services and Government Relations. He also coordinated the activities of the Family Council and program advisory committees and served as family advocate.

He represented Bancroft on the Board of ABCD and the Legislation and Policy Committee of the New Jersey Association of Community Providers (NJACP). Previously at Bancroft, Dr. Keating was responsible for the operations of the residential and day programs supporting adults with intellectual and developmental disabilities and acquired brain injuries. Dr. Keating represented ABCD on the Contracted Services Committee, a group of provider agencies that

met regularly with Division of Developmental Disabilities officials from 2008 to 2011. He served as co-chair from 2010 to 2011.

Keating received a doctorate degree from Temple University. He was an adjunct faculty member of the Psychology Department at Drexel University and the Human Services Department at Camden County College.



Pioneering disability rights, Dr. Keating helped launch one of the first residential programs and day programs for people with brain injuries. He also helped develop a comprehensive acute and post-acute rehabilitation programs for people with brain injuries.

He was also a founding member and past president of the Academy for the Certification of Brain Injury Specialists. Notably, he was a certified brain-injury specialist trainer.

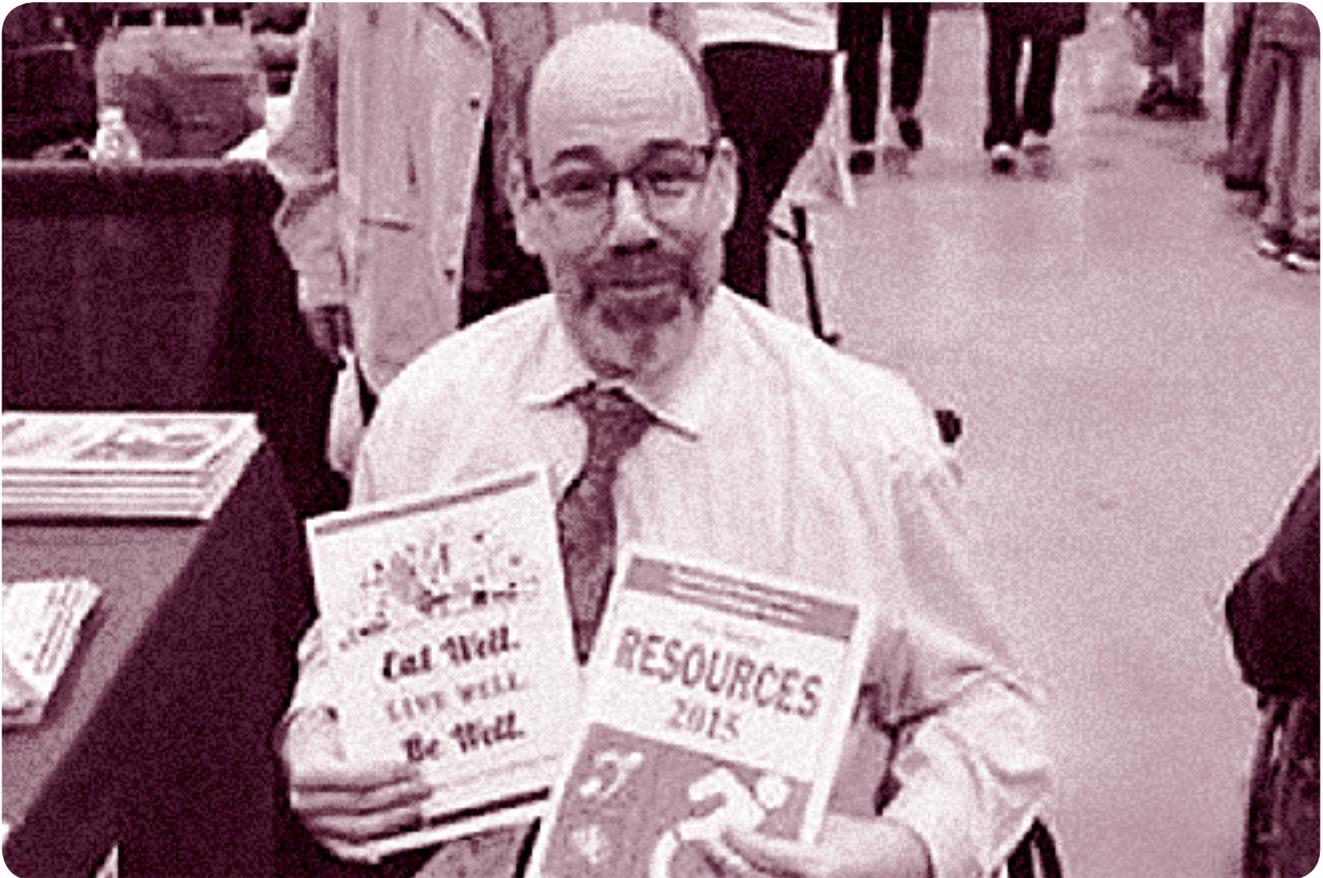
Former colleague Brian Duke provided the following comment on the website tribute wall for James J. Terry Funeral Home, where Keating’s memorial service was held:

“Dan was a man of wisdom and compassion. He was a great colleague during years at Bryn Mawr Rehab and we were able to connect every so often since that time. I am grateful for his leadership and advocacy which improved the lives of many people. Personally, I remain grateful for his support and counsel. Through his kind and peaceful manner, he was able to help a fellow person on their journey.”

Dan Keating will always be remembered for helping improve the lives of people with disabilities and thoughtfully supporting his many friends and colleagues. His immeasurable contributions will have a long-lasting impact. **P&F**

# Tribute: In Memory of Joseph Amoroso

By Jeremy Einbinder



Joe Amoroso, the former director of the New Jersey Division of Disability Services, passed away in September.

Amoroso will be remembered as a tireless advocate for the rights of people with all kinds of disabilities, especially by his former colleagues and those who worked for him. Amoroso attended Montclair State University and was employed as the school's first disability services coordinator. After completing his master's degree and a stint at Prudential Insurance, he began his employment with the The New Jersey Department of Human Services, Division of Disability Services. He first worked as the manager of Information and Referral before his appointment as division director.

Peri Nearon, who now holds Amoroso's former position, was very much impacted by his work, saying:

"While my style of leadership is a bit different, I would never want to lose sight of the central mission, which is to provide top-notch, comprehensive assistance. Joe knew firsthand, as an individual with a disability, that sometimes you really need an advocate sitting somewhere with the ability to make things happen."

Nearon is excited to have the opportunity to lead the division and focus on inclusive communities in addition to the work they do connecting people with the services they need.

"I would like to think that Joe would appreciate this broadened focus, and would see the value and necessity of moving in this direction," she said. She looks forward to carrying out both Joe's priorities and her own.

Renee Davidson worked under Amoroso as the program manager of the Personal Preference

Program, an alternative delivery service for Medicaid recipients. Davidson said that as a boss, Amoroso was always very supportive, but even before then, he was instrumental in Davidson's professional success, as he strongly encouraged her to apply to grad school. Amoroso advised her not to give up. Amoroso's passion for not giving up was evident through his work.

"Most people work to get a paycheck so that they can live. Joe actually lived to work." Davidson, now with a master's in social work, said that Amoroso worked tirelessly.

According to Davidson, when he taught classes to people at The College of New Jersey, his toughness was evident: "He didn't treat [the students] like children or baby them just because they had a disability. He treated them like an adult and tried to instill in them what it would be like in the real world, working in the workplace."

Davidson also noted Amoroso's sense of humor, recounting a prank in which he wrapped supplies from the office and presented them to colleagues as Secret Santa gifts.



Amy Tacklif, another one of Amoroso's former colleagues at the Division of Disability Services worked with him from 2005-2008. Tacklif shared the following thoughts about Amoroso's lasting impact:

"Joe's legacy is in how he made people feel about their own disabilities and the disabilities of their loved ones. He challenged some real deeply ingrained biases and offered folks a lot of different ways to think about their situation: about their options, their rights, their humanity, their opportunities, and their needs. And of course, he routinely challenged the assumptions of the non-disabled—in meetings and offices and restaurants and drive through windows and public events—with his own signature blend of humor and pride. Which I already miss."

Joe Amoroso impacted so many lives and he will surely be missed.

"Joe's influence is in everything I do," Tacklif said. "It's in everything many people do." **P&F**

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# PARTNERS IN POLICYMAKING PROFILES

By Maryann B. Hunsberger

## Caroline King

### Supporting Independence through Bike Riding

John King was a little boy when his mother, Caroline King, decided to educate herself more about disabilities. Having a son with Down Syndrome and apraxia of speech required her to be the best advocate her son could have.

Over the years, her research into disability advocacy taught her a great deal. Yet, she wanted to know more. In 2013, she found Partners in Policymaking (Partners), an 8-month leadership development and advocacy education program for adults with developmental disabilities and family members. It is funded through the New Jersey Council on Developmental Disabilities (NJCDD) and now available through a partnership between the NJCDD, The Boggs Center on Developmental Disabilities and Disability Rights New Jersey.

The Woolwich Township resident said Partners was “the most beneficial program I ever attended. It was educational, informative and empowering. I learned about the background of disability advocacy in New Jersey. Going to Partners gave me the confidence to look for a project that I was passionate about.”

After graduating, she and her husband David enrolled John in a five-day Pennsylvania bike camp operated by a nonprofit called iCan Shine. Through their iCan Bike program, the agency

conducts more than 100 five-day bike camps and after-school programs throughout the US and Canada, teaching 3,000 individuals with disabilities how to ride a bicycle each year. Since 2007, they have taught 20,000 children and adults with disabilities how to ride bicycles.

John had never learned to ride a bike because he has low muscle tone. “At camp, staying on the bike was the hardest part for him. I saw how the volunteers worked to keep John focused and how they encouraged him to pedal,” said King. “They kept him motivated to stay on the bike and ride. John left camp knowing how to ride independently. Before camp, swimming and horseback riding had been his priorities. After camp, bike riding became a priority for him.”

King realized she had found her project. “I knew I had to bring this camp to New Jersey.

I didn’t know it when I was at Partners, but bike camp was what came out of it.”

The Kings funded New Jersey’s iCan Bike camp at the Riverwinds Recreation Center in Deptford, New Jersey, located in Gloucester County. It was so successful that the Camden County Division of Events and Community Outreach picked up the program. “They completely support it. Camden County College offers their facility the last week in June,” said King.





*Pictured (L-R): volunteer, Rolando Otero, Caroline King, John King (Caroline's son) and Camden County Freeholder Deputy Director Ed McDonnell at the Bike Camp Volunteer Awards Ceremony in Voorhees, NJ.*

King and John, now 15, are still involved with the yearly program. For her efforts on behalf of children and adults with disabilities, the Camden County Board of Chosen Freeholders honored King during their monthly meeting on September 19, 2019.

Karen Weidner, Director of Camden County Programming for Individuals with Disabilities said, “To date, with Caroline’s first bike camp in Gloucester County and our subsequent six years following in Camden County, we have had more than 250 participants in bike camp. Caroline has volunteered at camp every year to ensure that things run smoothly and to cheer on our participants. She has been an amazing partner to me in making these camps successful and working with me to get participants and volunteers.”

King said all of their riders thought they could never learn to ride a two-wheeler. “Skills are involved—balance, steering and stopping.

So, we start teaching those skills in the gym. As they progress and can successfully ride inside, we transfer to the parking lot. The lot is reserved just for the riders. By the fourth day, 80 percent of the participants are riding a bike outside. In 2019, 100 percent were independently riding a two-wheeler in the lot by the fifth day.”

Each class is 75 minutes long, and each rider has a minimum of three buddies. It takes nearly 200 volunteers for a successful camp. King finds volunteers through word of mouth, and some organizations send professionals as part of their company volunteerism. She also contacts running clubs and high school athletic programs for volunteers. “They have to be able to keep up with the bikes and run alongside of them as the riders improve,” said King.

King said the key to their success is a combination of improving balance and using adaptive equipment. They lease and provide the adaptive equipment—a typical bike with a roller on the

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Camden County Freeholders presented commendations to bike camp volunteers. Pictured (L-R) volunteers Albert Busan, Matthew Parker, Shakur McFadden and Rolando Otero, Freeholder Susan Shin Angulo, Freeholder Deputy Director Ed McDonnell, Bike Camp Director Karen Weidner, John King (Caroline's son), volunteers Caroline King, Vicki Walters, Becca Gutwirth and Jenna Whelan.

back instead of a wheel. The roller is adjusted by size as the rider gains more confidence. After that comes a tandem bike, where the rider sits in front and a volunteer sits in back. Then, the rider transfers to a two-wheeler.

“Each person learns according to their own balance, leg strength and core muscle strength,” said King. “Besides leaving with improved balance, strength and bike riding skills, they all leave with an elevated sense of self-worth and accomplishment. The volunteers make this possible. Without them, there would be no bike camp.”

Age eight is the starting age for camp with no upper age limit. “A 50-year-old Collingswood woman, Kim Coll, learned to ride. She thought she couldn’t do it. Now she rides around Cooper Park in Cherry Hill.”

After camp ends, at least 15 minutes of bike riding per day is needed to retain skills, according to King. Therefore, she encourages parents to buy

a boardwalk style bike with hand brakes for their child. “This allows the rider to ride with friends, neighbors and family. Before John went to bike camp, we were never able to ride as a family. Now we can.”

King stressed that the confidence she gained by going to Partners made bike camp possible. Her increased confidence also resulted in forming a student teacher organization for parents of students with disabilities. “When I told my son’s school about Partners, they immediately agreed to form a group. Frank Latham from the Council was one of our first speakers.” She has also spoken at schools about person-first language, which she learned at Partners. “I wanted to alert people to let them know how to speak about someone with a disability.”

In addition, King asked a provider agency to host an open forum to answer questions from residents about community residences in Woolwich Township. “DHS (the Department of Human

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## PARTNERS IN POLICYMAKING PROFILES

Services) sent a representative to answer questions. I didn't want people getting their answers from social media. The neighbors got accurate facts and accurate reporting by the press because of DHS being involved."

The theme of the Partners group King attended was *You Hold the Power to Open Doors*. "It really did give people the power to seek

positions on school boards and to start programs they are passionate about. As a parent of an individual with disabilities, I wanted our son to blend with his peers. Partners gave me the courage to embrace John and his disabilities so he can shine and succeed with proper supports."

Those interested in volunteering or learning to ride can contact [icanbikenj@yahoo.com](mailto:icanbikenj@yahoo.com).

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### Lily Yip and Edna Antonian The Partners 2018 Advocacy Team

Lily Yip has been advocating for her children, Nicole Lee, 25, and Eric Lee, 23, since they were diagnosed with autism and intellectual disabilities 20 years ago. She left an information technology career in the corporate world in 2016 to focus on advocacy.

Yip signed up for the 2018-2019 Partners class, wanting to learn best practices in advocacy and to network with other families. The experience of meeting other parents was invaluable to her. "When you meet a family outside of the disability world, you have to explain the whole disability thing. With Partners, I didn't have to explain anything," said Yip. "It felt like home. On Friday nights after class, we would meet at the hotel bar and chat and enjoy ourselves. It was nice to have that social component with other families."

Despite years of advocating for her children, Yip learned new things at Partners. "I gained so much from the speakers every month. I learned that inclusion is possible in any situation. I didn't know that before, so it really stuck out to me. I also learned about the different laws and policies that are in effect and how they came about, such as the ADA and IDEA."

The number of self-advocates in attendance surprised Yip. "It was really eye opening. I gained a lot from working with self-advocates. I had already gone to some self-advocacy meetings with my son, but Partners took it to another level. It helped me realize my kids could be self-advocates. I also learned a great deal about policymaking.



Lily Yip, left, of Basking Ridge NJ, who took part in Partners in Policy Making 2018, and Edna Antonian, right, also was on Partners advocacy team.

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I never knew how much impact families could make in determining policy."

Since each Partners attendee works on a project, the Basking Ridge resident and another parent, Edna Antonian, Ph.D., of Mendham, chose to work together on housing. Antonian is the parent of a 29-year-old son. The duo decided to continue putting their newfound skills to work after graduating from Partners. They call themselves The Partners 2018 Advocacy Team.

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## PARTNERS IN POLICYMAKING PROFILES

Antonian said the most important thing she learned at Partners is that “parents are the biggest assets in the lives of their disabled children for bringing about major legislative changes. [They can do this] by advocating for their loved ones for their civil rights, their benefits, new laws and improving their support systems. I have found that to be effective you need to speak to the few right people and get your message across, instead of [going to] big conferences or just complaining about the way things are going and giving up.”

Therefore, Antonian contacted Paul Aronsohn, whom Governor Phil Murphy appointed as Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families in 2018. She invited him to a meeting at the Morris County Library in Whippany. She also reached out to some parents of children with disabilities, who came and spoke up.

Aronsohn listened to the families’ stories and their ideas of how to tackle housing issues. Yip said, “Since he started in office, he has been focusing on what’s needed and what’s not working and he wrote a report about many different topics relevant to parents of children with disabilities. At our meeting, we proposed what we wanted and he listened and took notes. He can’t change the law, but he works with legislators who could possibly change the law.” Yip said the parents who came to the meeting will continue meeting as an ongoing group. They already had another meeting and sent a follow up email to Aronsohn.

The group’s focus is on housing because of the housing crisis “for this subset of the population. A child with autism will become an adult with autism who will most likely need help for the rest of his or her life. That doesn’t even count the other developmental disabilities. The state isn’t in the housing business, so it’s up to parents to come up with progressive solutions, such as group homes owned by families. Some places have employment and housing on the same property. There is also shared housing run by nonprofits where people with and without disabilities share the house. We want to provide families with a lot of different options, as one model doesn’t fit all. We’d like to change the laws to benefit the families.”

The duo is working with legislators to do exactly that. “We’re working on a law that would give property tax breaks for families who own the houses used as group homes,” said Yip. “For example, veterans and seniors have a tax break for privately owned housing, but there’s none for families owning homes for people with developmental disabilities.”

Eventually, the team plans to put all the information about housing on a website for families to learn about the various possibilities.

Yip and Antonian went to Partners alone, but came out of it with a teammate and a group of parents. Yip said, “At graduation, everyone had to make a short speech; I spoke about how connecting with the other parents gave us motivation because we knew we weren’t alone.”

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### Kailas Rangachar

#### Learning to Be Independent

As the mother of a 25-year-old son with a developmental disability, Sumana Rangachar attended Partners 2017-2018 to learn more effective advocacy methods. She accomplished that mission, and also piqued the interest of her son, Kailas Rangachar. Kailas, who lived in Montclair at the time, chose to attend the 2018-2019 class and

found Partners to be “a worthwhile experience.”

One of his goals for Partners was to learn how to give students with disabilities a better experience than he had in school. “I went to Partners to talk to people about reforming the policies of people with disabilities in schools and in the workforce. I learned there’s a lot of work to be done. One

## PARTNERS IN POLICYMAKING PROFILES

of my main interests is to get more paraprofessionals [instructional assistants/aides] who are trained to work with students. I had a paraprofessional when I was young who wasn't very good. Paraprofessionals need to be better trained to look out for students. I also want to see more funding for services for young adults seeking out employment, especially for transportation, job coaching and vocational rehabilitation services."

One of his favorite things about Partners was the camaraderie. "I liked how we all had passion for the same things and all were able to move forward in agreement, making our cause a lot stronger. We all supported each other."

Through Partners, Rangachar grew as a person. "I learned that it's good to ask for help and it's not a weakness to need help. I learned that many people with disabilities are hesitant to reach out to others. I've been one of them. Now, I don't feel that way as much. I'm a lot more able to make calls and talk about things now. I found out that I'm not alone and there are a lot of people like me. I feel less isolated now."

Rangachar also enjoyed the social aspect of the program. "The whole program was fun and we got to do things like playing pool together in the hotel. It was my first time alone at a hotel. I enjoyed the feeling of independence."

Rangachar already had a job at Five Guys when he went to Partners. He takes college classes, and hopes to obtain an associate's degree in either psychology or math. He has completed 40 out of 60 credits so far. "A lot of people at Partners gave me advice on careers and how to use vocational rehabilitation services to find a better job eventually. But, I don't currently use any supports for academics or vocational rehabilitation. I got the job on my own and I work without a job coach. It wasn't until two years ago that I reached the point of being able to work without assistance. I now do all the things I need to do on my own."

His mother said, "Kailas made goals through Partners and he's trying to make them happen. His biggest goals are to be independent, live on his own and get a job with benefits."



*Kailas Rangachar working at Five Guys in White Plains, NY*

He also intends to keep working on his Partners goals. "I plan on advocating for others now. I've gotten good at standing up for myself, and I'd like to spend more time thinking about advocating for others. I applied for a paraprofessional job at a school for students on the spectrum. If I want to see better paraprofessionals, becoming one is a start."

Kailas Rangachar would recommend that others attend Partners to learn to advocate. "Other people with disabilities would learn how to motivate themselves to turn their situations around. For me, it was going in and finding things I can do for myself rather than feeling helpless. In school, everyone else did things for me. At Partners, I did everything for myself and learned how to keep doing that. I feel more independent now. It's a much better feeling to do things on your own." **P&F**

# DDD Fee-for-Service Self-Directed Models

By Gary L. Brown & Jonathan Jaffe

**S**elf-Directed Services is an approach to the delivery of home and community-based services that offers increased control and choice over how and from whom you receive support. The Self-Directed Employee (SDE) option for self-directing services enables you (or your representative) to recruit, hire and manage employees to provide prior authorized direct support services.

The NJ Department of Human Services, Division of Developmental Disabilities offers two SDE models for people who choose self-direct services:

- Vendor Fiscal/Employer Agent (VF/EA)
- Agency with Choice (AWC)

Note: Families may still choose the traditional agency model for both in-home and out-of-home services and supports.

## ***What are the differences between the two SDE models?***

There are two main differences between the VF/EA and AWC models: who is identified as the employer of record and the availability of employer-sponsored health benefits and paid time off.

In the VF/EA model, the individual must enroll as the employer of record and obtain a Federal Employer Identification Number (EIN), or authorize someone else to enroll as the employer of record. In the AWC model, the fiscal intermediary (FI) is the employer of record and the individual is the managing co-employer.

Employer-sponsored health benefits are not available in the VF/EA model. Health benefits are

available in the AWC model to employees working 30 or more hours per week for the employer of record (Easterseals). An SDE contributes to their health benefit costs.

## ***How do I decide which model is right for me?***

It depends on your needs and preferences. Your budget must support the cost of participation. You should discuss service options with your support coordinator and planning team members to determine which option is best.

## ***How do I enroll?***

Tell your support coordinator you are interested in hiring self-directed employees through a SDE model. When you decide which model best meets your needs, your support coordinator will send an individual referral to the appropriate FI. The FI will contact you within 3-5 days to initiate the enrollment process.

## ***How soon after enrollment can my employee start working?***

A self-directed employee can provide services after the following conditions are met:

- The FI confirms the employee completed the hiring process,
- The FI provides the correct billable unit rate to the support coordinator,
- And the service is included and approved in the Individualized Service Plan.

**Editor's Note:** Webinars and resources are available at: [www.state.nj.us/humanservices/ddd/programs/selfdirected/](http://www.state.nj.us/humanservices/ddd/programs/selfdirected/)  
Please refer to the site periodically as new information is added.

### ***Is there a cost to participate in either of the models?***

Costs are associated with each model, including a monthly fee and the cost to cover Workers' Compensation insurance and employer-related taxes. The state pays for an individual's participation in the VF/EA model and partially covers an individual's participation in the AWC model.

The additional cost to participate in the AWC model is primarily due to the availability of health benefits. The cost is deducted monthly from the individual's budget.

### ***Do employees get paid time off in either model?***

In the VF/EA model, sick time only is available and accrues one hour per every 30 hours worked. In the AWC model, paid time off is available to every employee and varies based on the number of hours and number of years worked for the FI (Easterseals).

### ***Who determines my employee's hourly wage?***

In both models, you determine the employee's hourly wage (within "reasonable and customary"). Your budget must be able to support the hourly wage. In both models, the FI increases the hourly wage to cover the cost of employer-related taxes. This results in a billable rate which comes out of the individual's budget.

### ***Can I hire a family member for either model?***

Yes, you can hire a family member in both models if the family member is not your parent (biological, step, or adoptive parent), guardian or spouse.

### ***What if I already have self-directed employees?***

If you have self-directed employees in the VF/EA model with Public Partnerships, you can continue in that model or transition to the new AWC model.

If you have self-directed employees with Easterseals, you have probably not transitioned

into fee for service. You must transition into fee-for-service and decide which self-directed employee model, if any, you will participate in.

### ***What if I receive self-directed services from a community vendor?***

If you ONLY receive self-directed services from a community vendor (for example, through Goods & Services) and do not have self-directed employees, you must continue to use the VF/EA model with Public Partnerships.

If you receive self-directed services from a community vendor AND you have self-directed employees, you will have the option to participate in the VF/EA model with Public Partnerships for all your self-directed services or you may choose to participate in the AWC model with Easterseals for all of your self-directed services.

### ***Can I participate in both models at the same time?***

No. You can only participate in one model at a time. You have the ability to change from one model to another based on your needs and preferences.

### ***What if I receive DDD services from a self-directed employee and I receive services through the Personal Preference Program (PPP)?***

Public Partnerships will continue to be the fiscal intermediary for all Personal Preference Program (PPP) services.

If you receive DDD services from a self-directed employee through Public Partnerships and you receive PPP services, you have the option to either:

- (a) Continue with Public Partnerships Limited for both DDD and PPP services, or
- (b) Transition to the Agency with Choice model through Easterseals for your DDD services.

If you receive DDD services from a self-directed employee in the old Easterseals model and you receive PPP services, you can transition your DDD services to either the VF/EA or AWC model.

***Does this mean I can now use a single Employer Identification Number (EIN) for both my PPP services and my DDD self-directed employee services?***

No. Enrollment in PPP services requires you to obtain an EIN in your name. If you also choose to participate in the VF/EA model with Public Partnerships Limited, you cannot enroll using that same EIN. You must identify someone else who is willing and able to obtain a separate EIN and enroll as the employer on your behalf.

If there is no one who can obtain an EIN and enroll as the employer on your behalf, then you must participate in the AWC model or receive services from an agency.

***The Weissbach-Efrat Family: Vendor Fiscal/Employer Agent***

Throughout the week, three DSPs head to the Cherry Hill home of Lisa Weissbach-Efrat. They provide support for her son, Matan, who has severe autism and other challenges. All of these employees are hired, trained and managed by Weissbach-Efrat, and her husband, Dan.

The Weissbach-Efrat family participate in the VF/EA self-directed model.

In the VF/EA model, you must enroll as the employer of record and obtain a federal Employer Identification Number (EIN), or you must authorize someone else to enroll as the employer of record. Employer-sponsored health benefits and vacation days are not available in this VF/EA model.

The family, as the “employer of record” informs the fiscal intermediary (FI) about the number of hours each employee worked by completing a time sheet.

Then the FI provides payment to the SDE and deducts for all required payroll related taxes. In this case, the family works with Public Partnerships, which is under contract with the state Division of Developmental

Disabilities (DDD) to serve as the FI for the division’s Supports Program, Interim Program, and Community Care Program (CCP).

Through this program, Weissbach-Efrat works with a support coordinator to develop a spending plan for Matan’s needs and goals.

Typically, an SDE will work between five and eight hours in the Cherry Hill home. The family provides the overnight care.

“Matan is non-verbal and uses an iPad to communicate. He has a high activity level and needs a lot of exercise to self-regulate and sleep,” Weissbach-Efrat said. “Together, we need to



► Dan Efrat, dad, Matan Efrat, Nayeli Efrat, sister, and Lisa Weissbach-Efrat, mom, dog-Chuchi at home in Cherry Hill NJ.

exhaust him so he can sleep. Our support team is always helping him with his self-help skills. He really needs a lot of support.”

With the help of ever-present SDEs, Matan is learning how to do his own laundry and fold his own clothes. Workers help him peel vegetables, and dust around the house. They also help guide him through other basic cleaning routines.

Basic meal preparation is an ongoing lesson, requiring significant support. The team provides Matan with a set of pictures, including step-by-step procedures, constantly redirecting him to the task at hand.

“If it was up to Matan, he would just walk away,” his mother said. “He has a history of eloping, just taking off and running down the street. He functions at the level of a two or three-year-old, which is why we need trained people who can help us.”

Weissbach-Efrat notes the family could not function without the help of Public Partnerships Limited and the SDEs, noting Matan would likely be living in a group home. Rather, his 13-year-old sister can live a typical life, most of the time, with the SDEs focused on her brother’s needs throughout the day.

The family began working with Public Partnerships during July 2017, when DDD began its Medicaid fee-for-service program. At first, Weissbach-Efrat described it as “a nightmare.” She said the DSPs were not paid for the initial four months, as the program rolled out. Now, more than two years later, the program has minimal, if any, problems, she said.

Weissbach-Efrat, 50, says she has her own medical issues, making it impossible to care for Matan on her own.

She supports the FI model over working with an agency that recruits hires, and fires staff. “You are able to pay the staff what they are worth,” she said. “When you work through an agency, the agency needs to take some of the money just to cover the overhead. Plus, the employees at agencies keep coming and going because of the low pay. Before 2017, it was a revolving door here, working with agencies.”

Weissbach-Efrat said she is proud of how her employees are treated as part of the family. They participate in our birthday parties; their kids get holiday gifts. “If we eat out at a restaurant, of



▲ Matan Efrat folding his laundry.

course they come with us,” she said. “We are fortunate with the financial ability; they are always welcome to eat here.”

### **The Lerner Family: Agency with Choice**

Amy Lerner of East Windsor has a daughter, Carrie, with a genetic disorder. Carrie lives in an apartment in the family home, where she has a number of self-directed employees.

In the AWC model, the FI is the employer of record and the individual is the co-employer. Employer-sponsored health benefits are available in the AWC model to employees working 30 or more hours per week for the employer of record (Easterseals).

During the day, Carrie goes to a program. Her mother assists Carrie 13 hours a week when SDEs are not available. The rest of the support hours comes from SDEs.

With such a shortage of SDEs, and the need continuing to grow, Lerner is worried about relying on agencies down the line and “the strangers” that would ultimately come to care for her 38-year-old daughter.



◀ Amy Lerner and her daughter Carrie at their home in East Windsor NJ

“If the pay is low, how are we going to keep the employees?” Lerner asked. “You need to pay them a fair wage and give them benefits so they will want to stay in the long run.”

People choosing either model should review NJ Department of Labor and Workforce Development labor laws. Participants must ensure

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▼ Carrie Lerner and her music teacher Jim Gaven during a music lesson



that, in their role as employer of record or co-employer, they abide by those laws. For example, they must ensure that employees are not discriminated against. The fiscal intermediary for the SDE model selected can help answer questions related to your role and responsibilities.

## **The Smith Family:** *The Traditional Agency Model*

Meet Annette Smith of Newark, whose youngest daughter, Tiffany, requires total care throughout the day and night. Her 36-year-old daughter has cerebral palsy, is visually impaired, has epilepsy and intellectual disabilities.

Smith uses an agency called Divine Healthcare Services in East Orange, which provides trained staff as needed. Tiffany has a tracheotomy, and requires a feeding tube. A trained staff member needs to provide suction and maintenance throughout the day.

“They do an excellent job working with her; we love the agency,” said Smith, who works as a field support coordinator for Neighbours, Inc., which supports people with disabilities and their families in choosing and creating a life for themselves within their local towns and neighborhoods.

Tiffany has always lived at home, and has been served by agencies since she turned 21 years old. She has been on a feeding tube since she caught pneumonia and was hospitalized at Overlook Medical Center in Summit for six weeks in 2012.

“We couldn’t rely on home health aides anymore,” Smith said. “We need a staff with medical training. I went the agency route because of Tiffany’s medical condition and ensuring someone is trained properly to care for her.”

Smith said she is fortunate for all the support, noting her sister also lives with them in the two-family



◀ *Annette Smith and her daughter Tiffany. Right is Clover Minott, Tiffany's DSP at their home in Newark, NJ.*

home and is a trusted resource. In addition, Tiffany's sister, Alicia Wynn, of North Plainfield, is a DSP who works for Easter Seals and also helps out with care. But even with so many resources, Smith is always the "overnight person" to help Tiffany.

"Tiffany takes several seizure medications and she sleeps a lot," Smith said. "We use the budget to purchase a music person to come in twice a week for interaction and to keep her awake. The aides from the agency do a great job of interacting with Tiffany. They do what they can to stimulate her."

Smith said there are now two women from the agency who have been working with Tiffany for the last three years.

"They have been very good. The only problem is that they don't have health benefits and don't get vacation time. Still, since 2012, the agency has never left Tiffany's side," she said. "For that, I am so grateful." **P&F**

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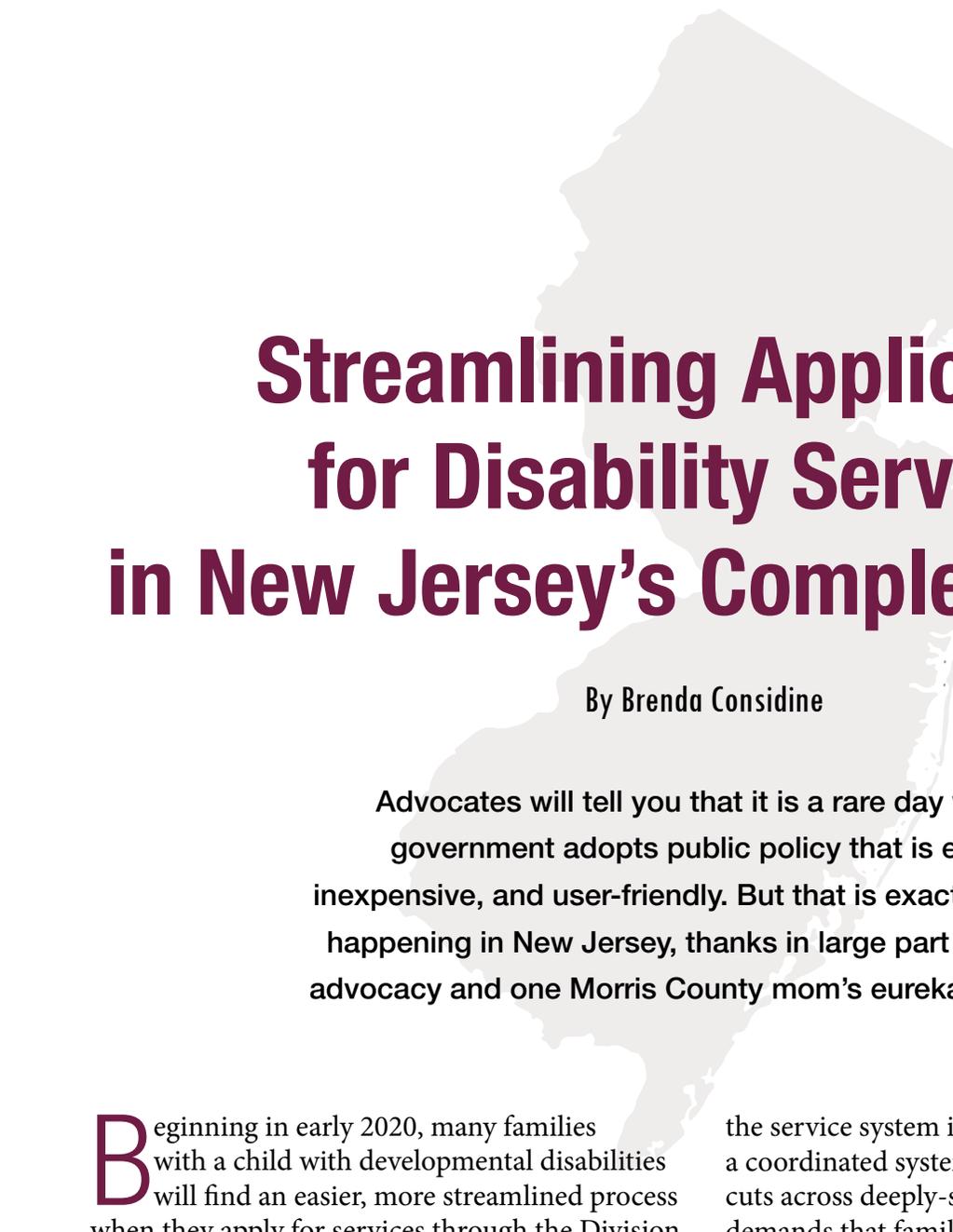
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# Streamlining Application for Disability Services in New Jersey's Complex System

By Brenda Considine

Advocates will tell you that it is a rare day when government adopts public policy that is easy, inexpensive, and user-friendly. But that is exactly what is happening in New Jersey, thanks in large part to family advocacy and one Morris County mom's eureka moment.

**B**eginning in early 2020, many families with a child with developmental disabilities will find an easier, more streamlined process when they apply for services through the Division of Developmental Disabilities (DDD) when their son or daughter turns 21. While they still have to fill out paperwork, they will no longer have to submit documentation to prove that their son or daughter has a developmental disability.

The change is simple and family-driven. It will save money, time, and reams of paperwork.

## The New Jersey System(s)

First, some background. Accessing disability services in New Jersey is an ongoing (some might say never-ending) process for people with developmental disabilities and their families, because

the service system is neither a single system nor a coordinated system. In fact, it is multi-faceted, cuts across deeply-siloed state systems, and demands that families reapply for services over and over again as their child ages, in the hopes of maintaining continuity of services.

When a child with a suspected disability is under the age of three, the child and family may be eligible for Early Intervention Services provided through the Department of Health. That system has its own intake and eligibility process. Once deemed eligible, families and their infants and toddlers can receive services such as speech and physical therapy, although they may have to pay for them.

Then, at age three, that same child might receive special education services through their

local school district, under the auspices of the Department of Education. That system has a different application and eligibility process, and requires a set of evaluations. Once the child is deemed eligible for special education, services are guaranteed under federal law and are provided free to families. Services must be individualized and appropriate to the needs of the child. They are provided as long as needed or through the end of the school year in which the child turns 21, whichever comes first. Special education and related services—including transportation, therapies, and summer learning—are provided through this system, with re-evaluation offered every three years.

If a child and their family need more support outside of school hours, perhaps respite care or other supports, yet another state department steps in. Within the Department of Children and Families, a program called the Children's System of Care (CSoC) provides support, respite, camperships, in-home behavioral supports, crisis support, and at times, funding for residential services. (NOTE: Residential services can also be funded through the local school district, when they are needed in order for the child to benefit from special education.)

Once again, there is a new application process, a new eligibility process, more paperwork, and more waiting. CSoC requires assessment and evaluation to be less than a year old, and requires families to re-apply for services periodically. The application process is so onerous that nearly half of the families who begin the application process simply give up and go without services.

Then, at age 21, services through CSoC and DOE come to an end, and become DDD's responsibility. Once again, families face yet another eligibility and application process. And once again, they have to fill out paperwork, provide evaluations, and prove, yet again, that their child has a developmental disability.

It should be easier. In fact, in 2001, New Jersey established the Developmentally Disabled Uniform Application Act. The Act requires the

Departments of Health, Human Services, and Education to develop and exchange information to facilitate application for disability services.

## **A Small Change with a Big Effect**

Here is where the good news begins. By 2020, young adults who have been receiving services through the Children's System of Care (CSoC) will find a more streamlined process as they age out of that system at age 21 and become eligible for DDD. As part of the application for DDD services, the presence of a developmental disability will be presumed, based on eligibility for services through CSoC.

The change in policy is being implemented because of advocacy initiated by Gabrielle Bohon, a Morris County advocate who serves as Vice-Chair of the Statewide Regional Family Support Planning Council, and is a member of the New Jersey Council on Developmental Disabilities' Sub-Committee on Children and Youth.

Bohon said the idea hit her like a "lightning bolt."

"It occurred to me: we have already proven that our child has a developmental disability when we apply to CSoC for family support services; why do we have to prove it again? My daughter has Down Syndrome. That extra chromosome is not going to disappear when she turns 21," said Bohon.

A lawyer by profession, Bohon knew she needed to do her homework. Research led her to a 2002 "Letter of Agreement" between the Department of Education and the Department of Human Services, outlining a uniform application process. The Initial Uniform Application Act, which became effective in September 2001, was intended to make it easier for parents of children with disabilities to access services from participating agencies by facilitating the exchange of information among agencies.

The letter and the Act pre-dated the role of CSoC, but said if a child gets DDD services before they are three, they do not need to re-prove the presence of a disability again at age 21.

Bohon took the letter and made her case to DDD, based not only on what is good for families, but also on what is good for government.

“It costs money to do this twice and it makes no sense. From a public policy point of view, there is a state employee who has to write, read, and process the paperwork—it is redundant and inefficient. The money could be dedicated to services,” said Bohon.

She pitched the idea to DDD’s James Schiralli, the statewide intake director, who agreed.

“It simply made sense to streamline the application process,” said Schiralli.

“The change makes it easier for individuals to move from children’s services to adult services. It makes it possible for the individual’s disability-related information and eligibility for developmental disability services to transfer more seamlessly from one system to the other,” he added.

Schiralli confirmed that, historically, there had been a single application for eligibility used by anyone seeking developmental disability services in New Jersey. In 2013, however, when developmental disability services for children under 21 transitioned from DDD to CSoC, two separate eligibility applications began to be required: a CSoC application for individuals under 18, and a DDD application for individuals 18 and older (even though services for individuals 18-21 are accessed through CSoC).

“The information captured by the two applications is largely the same, so we are going to streamline this process,” he said.

In addition to the full application for eligibility, DDD developed a short application for eligibility that can be used by individuals who are already enrolled in or receiving services from CSoC. The short application requires the individual to enter only essential demographic information, as well as their CSoC identification number and care manager. Using the CSoC information, DDD can contact CSoC directly to request the individual’s disability-related information.

Schiralli believes that once the short application is in place, it will make it easier for individuals enrolled in or receiving services from CSoC to transition to DDD and the adult service system.

“It is important to note that the full application for eligibility will still need to be completed for individuals 18 and older who never enrolled with CSoC and who only access developmental disability services through their school district,” said Schiralli.

The new short application is expected to be available for use by winter 2020.

The process of changing the application process—from concept to commitment—took Bohon several months.

“By participating in New Jersey Regional Family Support Planning Council sub-committee meetings, I came to understand how CSoC collected and handled its data so it could be easily transmitted to DDD. I had to make certain that the connections between the two departments were made. My fellow committee members were very patient, allowing me to ask the same questions at meetings,” she said.

## Still More to Do

While the new streamlined eligibility is a step in the right direction, advocates agree there is plenty of room for improvement.

Bohon’s next goal is to get the CSoC application process to align with that of school district IEPs.

“CSoC requires that many evaluations not be more than a year old, but the school system only does evaluations every three years. That means families have to spend money on an evaluation and wait for the reports, when the DOE has already decided that my child has a disability and needs services. It does not make any sense,” she said.

She would like to broaden and match the IDEA’s triennial requirements but said, “that will be a tougher nut to crack. Ideally, New Jersey should return to the 2001 Uniform Application Act and simply expand its use,” said Bohon.

Lisa Parles is an attorney and founding partner at Parles Rekem, a law firm in Union County specializing in disability law. The parent of a man with severe autism and an active advocate for systems change, Parles handles many cases for clients with complex needs addressed across service systems, including DDD and CSoC.

She would like to see the DDD application process be automated.

## THE FAMILY SUPPORT ACT OF 1993

CSoC is responsible for providing family support services, as defined by the 1993 Family Support Act.

The Family Support Act of 1993 is based on the underlying premise that families are the best judges of what they need. Family Support means serving the person with a disability AND the entire family. It means not leaving anyone out of the picture.

### The Family Support Program includes:

- cash subsidies
- communication and interpreter services
- counseling and crisis intervention
- day care
- equipment and supplies
- home and vehicle modifications
- homemaker assistance
- medical and dental care
- personal assistance services
- respite care
- self-advocacy training
- therapeutic or nursing services
- vouchers for services

### Family Support allows the families to:

- decide what services they need
- choose, control, and monitor their own services
- exchange vouchers for services they choose
- receive cash subsidies to purchase services.

The Family Support law also created Regional Family Support Planning Councils. The Councils make recommendations to a family support coordinator, under the direction of the New Jersey Council on Developmental Disabilities.

### What Does CSoC Offer Families?

Respite care

After-school activities

Weekend recreational activities

A short-term placement in a licensed setting

In-home respite

Self-directed respite

Camp

Assistive technology devices

Home and vehicle modifications such as ramps, grab bars, etc.

“Why do families even have to apply again? Why can’t the system just do that for the family, if someone is already in the system because of a disability: why make them apply all over again just because they turned 21?” she asked.

While eligibility between state departments is one problem; capacity, climate, and culture also vary greatly from one state department to another.

“I have handled cases in which people are in residential services, they clearly have I/DD. As soon as they turn 21, even if they are in school, they are forced to leave the residential placement

mid-year and come back to New Jersey, even if there is no place for them to go,” she said.

Parles agrees with Bohon that DDD has made improvements.

“DDD has created a Family Advisory Council (FAC) and they are really receptive. When we raise issues, they work with us to create FAQ sheets and other tools to help families. It is not perfect, but we are building an avenue to raise issues,” she said,

“There are still major holes in the system, but this is definitely a step in the right direction,” Parles concluded. **P&F**

**Editor's Note:** DDD announced the availability of the new short application while this issue of *People & Families* was being finalized. It is now available on line.

# DISPUTES AND DISAGREEMENTS IN SPECIAL EDUCATION



By Adam Wilson, Esq.

**N**avigating the special education system poses a unique challenge for parents. There is a lot on the line for special education students who in many cases are already behind their peers and cannot afford to waste time with ineffective educational programming.

As such, it is vital that a student's programming is appropriately tailored to their needs. However, the individual education program (IEP) development process is often confusing and resolving a dispute with a school district can seem like a daunting challenge. The good news is that most disagreements are settled without a lawyer. Parents must know their rights and be clear with the school district about what solutions they are seeking.

This Q&A addresses some common questions parents have about the IEP process. It also addresses how to deal with disagreements with a school district when they arise.

## ***What is an Individualized Education Program?***

An IEP is a written document which maps out the framework for a student's special education instruction. An IEP is developed through a meeting of the IEP team, which is ideally a collaborative process involving the parents, members of the school district's child study team, the child's teacher(s), and other individuals who are knowledgeable about the student's educational needs.

In developing an IEP, it helps to use a four-step framework for discussion:

- 1) Identify challenging but achievable educational goals.
- 2) Identify the barriers to those goals.
- 3) Create educational programming to overcome those barriers.
- 4) Determine the best placement for the student based on programming needs.

### **What is Included in an IEP?**

A well-written IEP will not only cover where the student will be placed, it will also include the programming and any related services (such as speech therapy, occupational therapy, etc.) the student will receive during the school year.

IEP programming is not limited to academic needs, but can also include daily living skills, social skills instruction, behavioral intervention, in-home programming, and other instruction necessary to ensure the student benefits from their education. In essence, the IEP should be designed to include all services in all locations necessary to ensure the student is appropriately challenged and making progress. Disagreements are not limited to simply where the student is placed, but can cover any aspect of the IEP such as extended school year instruction, the intensity and duration of therapies and related services, transportation services and supports, aids and paraprofessionals, etc.

### **What Happens If I Don't Agree With My Child's IEP?**

If you have specific concerns heading into an IEP meeting, you should share a written list with the child study team before the meeting. You should provide enough detail to ensure the child study team members understand your concern and why it is a concern. You should also specify exactly what you're requesting to address the concern. When a written list is shared in advance, it can help streamline the meeting conversation to focus on specific disagreements. It also ensures that your concerns are not lost or glossed over during the meeting.

You should not sign the IEP unless it contains everything your child needs to make meaningful

educational progress. If you don't agree with a proposed IEP, you can write a letter to the child study team describing specific changes and the reasons why you are requesting those changes. The key is to clearly communicate exactly what you're looking for. If the child study team refuses to make changes, you can request a meeting with the director of special services or the superintendent.

### **Important Note:**

*Even if you don't sign your child's IEP, it will still go into effect after 15 days unless the school district agrees to delay implementation of the IEP or you file for mediation or due process before 15 days elapse. More information this issue and a vitally important right called "stay-put" is contained below.*

### **What Happens If a Dispute Cannot Be Resolved With District Staff?**

If informal avenues or resolving your disagreement are not producing results, you can request a facilitated IEP meeting, mediation, or a due process hearing.

### **A Facilitated IEP**

A facilitated IEP is developed with the help of a third-party called a "facilitator" who is provided by the New Jersey Department of Education. The facilitator is not a member of the IEP team, and does not advocate for either side. Rather, the facilitator's job is to ensure effective communication between all parties and to keep the meeting focused on the student's needs. A request for a facilitated IEP can be made by either parents of the school district, but must be agreed upon by both parties. A facilitated IEP can sometimes be a good way to resolve disputes with a school district before they escalate.

### **Mediation**

Mediation is an informal procedure in which a representative from the Office of Special Education Programs meets with parents and representatives from the school district in an attempt



*Mediation helps identify and resolve disputes with an enforceable settlement agreement.*

to resolve the dispute. Similar to a “facilitator”, the mediator is an independent third-party who is not advocating on behalf of either party. However, mediation is different from a facilitated IEP meeting because mediation is focused on identifying and resolving existing disputes with an enforceable settlement agreement rather than simply a new IEP. You can’t “lose” a mediation. Either you walk away with a satisfactory settlement agreement, or you don’t. A request for mediation is voluntary and can be initiated by a parent. School districts almost always agree to participate in the process. You are not required to participate in mediation before a due process hearing.

### ***Due Process Hearings***

A due process hearing is a trial-like proceeding held before an administrative law judge. A hearing can be requested regarding eligibility, classification, placement, or any of the student’s educational programming. Both parents and the school district can call witnesses to testify. Each witness

is subject to cross-examination. At a due process hearing in New Jersey, the school district presents its case first and has the burden of proof. This means the school district must prove the IEP is

### **Attorney’s Fees**

There are two ways to recoup attorneys’ fees. First, they can be included as part of a settlement during the mediation or the due process proceedings. However, in New Jersey school districts are often unwilling to include attorneys’ fees as part of settlement. Second, if a parent is successful at a due process hearing and receives a favorable ruling from the Administrative Law Judge, parents can make an application to have the school district reimburse the costs of the hearing including attorneys’ fees and expert witnesses.

appropriate for the student in light of the student's individual needs. The hearings are recorded and free testimony transcripts can be obtained.. Legal briefs are often submitted after a trial. After the hearing and brief reviews, the judge will issue a binding decision for all parties.

Either party may pursue an appeal of the judge's decision to either state or federal courts. Parents can also use the courts to enforce an administrative law judge's decision when a school district fails to implement that decision.

### **What Happens to My Child's Programming During an Appeal?**

One of the most remarkable rights in special education is commonly referred to as "stay-put" or "pendency", but you must act quickly to preserve this right. If a school district issues a written recommendation to change your child's programming or placement (which typically occurs when the district issues a new IEP) you can prevent that change from being implemented by filing for mediation or due process within fifteen (15) calendar days of when the change was recommended.

During the entirety of either mediation or due process proceedings, no alteration may be made

to your child's program unless both you and the school district agree to the change.

#### **Important Note:**

*You must file for mediation or due process within 15 days of the school district recommending a change in programming or placement. Even if you do not sign a proposed IEP, the IEP will automatically go into effect after 15 days unless the district agrees not to implement the IEP or your file for mediation or due process.*

### **What Happens in an Emergency?**

In New Jersey a typical due process hearing moves slowly. It can sometimes be a year or more from when you file a request for due process until an administrative law judge issues their decision. Emergent relief is available, but only when it is necessary. Emergent relief is often used if there is a break in services for the student, such as if the student is discharged from one program but the district fails to provide a new program or interim services while a new program is being located. **P&F**

Adam P. Wilson, Esq., is an attorney with Hinkle, Prior and Fischer, a New Jersey based law firm specializing in disability law. He joined the firm in 2013 and is well-versed in all areas of disability law. He focuses on guardianships, special education, and estate and trust matters. He frequently speaks on a variety of topics affecting the special needs community and also teaches a continuing legal education course on the fundamentals of estate planning. Adam graduated from Temple University-Beasley School of Law with a Master of Laws (LL.M.) in taxation and received his Juris Doctorate at Rutgers School of Law, graduating Cum Laude. He holds two undergraduate degrees from Pennsylvania State University, graduating with high honors.



Throughout his schooling and professional life Adam has demonstrated a commitment to serving vulnerable populations. He currently volunteers on the Board of Directors of the Planned Lifetime Assistance Network of New Jersey, a non-profit organization providing care coordination, guardianship, and trustee services for individuals with special needs. He also volunteers as a supervising attorney for the Rutgers Law School Preparing Estates Pro Bono program which drafts wills, powers of attorney, and medical directives for indigent people in Camden and the surrounding area.

Adam is an avid traveler and lover of the great outdoors. He lives in Philadelphia with his wife, Samantha, and their dog.

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

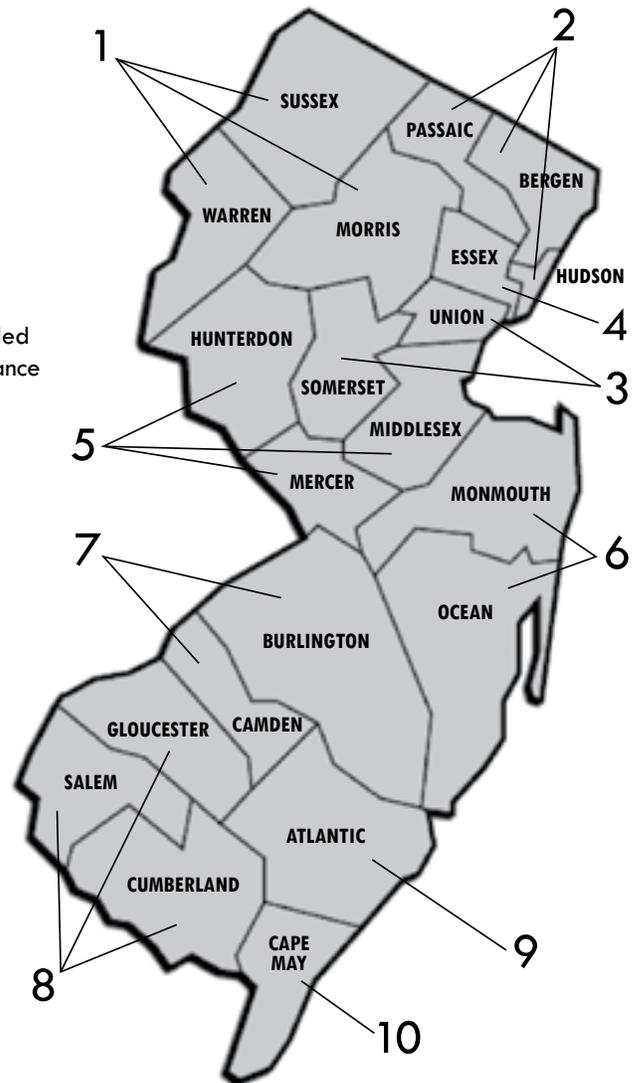
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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](http://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.njccd.org](http://www.njccd.org),  
click on the link for Family Support, and the number corresponding to the  
Regional Family Support Planning Council in your area.

## **1 SUSSEX, WARREN, MORRIS**

**RFSPC #1**  
**e-mail: [rfspc1@gmail.com](mailto:rfspc1@gmail.com)**  
**Chair: Margaret Hefferle**

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

## **2 BERGEN, HUDSON, PASSAIC**

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

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**  
**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**  
**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  
7:00 p.m.—8:30 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  
Township of Lakewood  
Office of the Manager & Mayor  
231 Third Street  
Lakewood, NJ 08701  
7:30 p.m.—9:30 p.m.

## **7 BURLINGTON, CAMDEN**

**RFSPC #7**  
**e-mail: [rfspc7@gmail.com](mailto:rfspc7@gmail.com)**  
**Co-Chairs: Laura Kelly, Lisa Weissbach-Effrat**

Meets the second Thursday of the month  
Wegman's 2nd Floor Cafe  
2100 RT-70W  
Cherry Hill, NJ 08002  
**Odd numbered months noon**  
**Even numbered months 7pm**

## **8 CUMBERLAND, SALEM, GLOUCESTER**

**RFSPC #8**  
**e-mail: [RFSPC8@gmail.com](mailto:RFSPC8@gmail.com)**  
**Chair: Sandra Backensto**  
Meeting times and dates TBD

## **9 ATLANTIC**

**RFSPC #9**  
**e-mail: [RFSPC9@yahoo.com](mailto:RFSPC9@yahoo.com)**  
**Chair: Mary Ann Philippi**  
Meeting times and dates TBD  
Arc of Atlantic County  
6550 Delilah Rd., Suite 101  
Egg Harbor Twp., NJ 08234

## **10 CAPE MAY**

**RFSPC #10**  
**PO Box 199**  
**South Dennis, NJ 08245**  
**e-mail: [RFSPC10@yahoo.com](mailto:RFSPC10@yahoo.com)**  
**Chair: Anne Berger**  
**Vice-Chair: Rose Kuprianov**  
Meets the third Thursday of the month  
except January, April, July August, and  
December  
Cape May Special Services School  
148 Crest Haven Dr.  
Cape May Court House, NJ 08223  
6:30 p.m.—8:00 p.m.

# NJ Council on Developmental Disabilities Position Statement on Education

## Position

The New Jersey Council on Developmental Disabilities (NJCDD) endorses the findings of the US Congress regarding the education of children with disabilities contained in “The Developmental Disabilities Assistance & Bill of Rights Act of 2000” and the “Individuals with Disabilities Education Act” (IDEA):

“Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.<sup>1</sup>”

NJCDD recognizes that individualized appropriate educational instruction and related services must be provided by highly qualified teachers and service providers who understand their shared responsibility with parents, guardians and administrators for student success. Successful inclusive

education requires that education programs prepare all educators and administrators, not just those in ‘special education’, to effectively work with students with a wide range of needs. Schools, classrooms, programs and appropriate transportation must be physically and programmatically accessible to all students.

The Council supports the use of positive behavior interventions and supports on a school-wide basis as an effective way to improve school climate and prevent the use of negative discipline strategies and extreme measures such as restraint and seclusion. The NJCDD opposes the use of any measures that cause physical, emotional, or psychological pain or discomfort.

## Background Information

Education is a lifelong process that assists all individuals with attaining fulfilling, meaningful lives. Successful outcomes of an appropriate education for students with disabilities should be evidenced by employment and/or enrollment in postsecondary education classes, and meaningful en-



gagement in community life. Students with intellectual and/or developmental disabilities (I/DD) have the right to learn with students their own age, with and without disabilities, in the same schools, classrooms, and other educational and extracurricular programs.

The right to an individualized education for students with disabilities is legally mandated by IDEA. Under IDEA, every child with a disability that impacts his or her ability to learn is entitled to a “free appropriate public education” (FAPE) in the least restrictive environment. Students with I/DD must be provided opportunities for inclusive and integrated academic and vocational instruction, and evidence-informed supports. A continuum of alternative placements must also be considered.

The importance of student participation in their own education and individualized education plan (IEP) development cannot be over-emphasized. Individualized, student-centered approaches used in IEP development are important to the achievement of meaningful outcomes and successful transitions to adult life. **P&F**

Adopted: 9-11-19



# SEVA

Special Education  
Volunteer Advocates

[www.spanadvocacy.org/SEVA](http://www.spanadvocacy.org/SEVA)

Supporting & Empowering Parents on their Advocacy Journey

## WHY SEVA?

- ✓ Need support at your IEP meeting?
- ✓ Want to improve your advocacy skills?
- ✓ Have a student in need of transition to adult life services?
- ✓ Seeking a more inclusive setting for your child?



## SEVA Provides

- ✓ Trained volunteers to support families at IEP and related meetings.
- ✓ Coaching to assist families in developing their advocacy skills.
- ✓ Information & resources for families.



Contact Jeannette to learn more:

[jmeijas@spanadvocacy.org](mailto:jmeijas@spanadvocacy.org)



# The New Jersey Council on Developmental Disabilities Position Statement on Employment

## Position

People with I/DD should have individualized supports to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination.<sup>1</sup>

The NJCDD recommends that the State take the following steps to effectively address the serious issues affecting unemployment for individuals with disabilities:

1. Vigorously enforce existing anti-discrimination laws
2. Effectively implement New Jersey's Employment First policy, by adopting the definition of employment as community-integrated paid employment with wages equal to or higher than the minimum wage
3. Engage and educate families, educators, service providers, and employers to ensure that individuals with I/DD develop real job skills and are prepared to seek, gain, and maintain meaningful integrated competitive employment that matches their strengths and interests
4. Ensure quality and responsiveness by monitoring the effectiveness of its service system to ensure it meets quality standards. Specifically, the State should regularly measure and report the extent to which services result in outcomes that successfully accommodate the

individual's unique needs and match the person's preferences, strengths, and interests. Moreover, the State should ensure, through agency coordination, that effective services and supports remain available as long as the person needs them to maintain successful employment.

## Background

A majority of individuals with intellectual and/or developmental disabilities (I/DD) are either unemployed or underemployed, despite their abilities, desire and willingness to work. This is true for our state and nation. Too often, unemployment is tragically accepted as an inevitable result of living with I/DD.

According to the National Conference of State Legislatures (NCSL), "...the employment of people with disabilities is seen not

only as a civil rights issue, but also as a practical boon for businesses, government budgets and citizens. Employing people with disabilities has been shown to benefit businesses. In addition, increasing job opportunities for people with disabilities 'saves the federal and state government money by reducing dependency on cash and medical and disability benefits,' per the (2018) Employer Assistance and Resource Network (EARN) . For people with disabilities, employment means greater economic self-sufficiency, an opportunity to use their skills, and more active participation in community life."<sup>2</sup> **P&F**

Adopted: 9-11-19

<sup>1</sup> Joint Statement of The Arc with the American Association on Intellectual and Developmental Disabilities (AAIDD), Employment Position Statement, 2012

<sup>2</sup> <http://www.askearn.org/>

# Disability in FOCUS

Presenting  
Facts

Sharing  
Views

Starting  
Conversations

Take a closer  
look at important  
DD issues!

Visit the NJCDD's blog, **Disability in Focus** each week to get the latest news and views from around the state and across the country about our developmental disabilities communities. And be sure to join the conversation by sharing your own views on the topics we discuss.

Make  
"Happen"  
EVERY DAY



We Can't Wait to Hear From You!  
Visit us at [www.njcdd.org](http://www.njcdd.org)



# Community Innovation Projects

The New Jersey Council on Developmental Disabilities' **Community Innovation Projects** encourage and fund **new** and **innovative** activities designed to bring about meaningful change at the local level. Funding up to \$10,000 for 12 months is available.

The primary goal is to produce short or long term system change. We want ideas that can be shared, disseminated and replicated.

## SUCCESSFUL COMMUNITY INNOVATION PROJECTS WILL:

- 1 Be related to the Council's 5-Year Plan.
- 2 Focus on advocacy, local capacity building, systems change, social change, equal access, community competence, or education of families and self-advocates.
- 3 Create and strengthen relationships with local associations and groups.
- 4 Position people with developmental disabilities and/or their family members as active and engaged participants who influence the work and participate directly.
- 5 Have a plan for the dissemination of successful practices.
- 6 Reflect the values, preferences, languages, and cultures of the communities they engage.

## INTERESTED?

Grant funds are intended to support short-term projects of up to 12 months and bidders can request funding in amounts up to \$10,000. To apply, please write us or email us a letter of interest ([grants@njcdd.org](mailto:grants@njcdd.org)) telling us:

1  
WHO  
YOU ARE?

2  
WHAT PROBLEM(S)  
YOU ARE TRYING TO  
ADDRESS?

3  
HOW YOU PLAN  
TO ADDRESS IT?

4  
HOW THIS RELATES  
TO THE COUNCIL'S  
5-YEAR PLAN?



Our review team will let you know if your concept aligns with our vision and, if so, we will invite you to complete the **Community Innovation Project application form** at <https://bit.ly/332X7D5>. We look forward to collaborating with you.



# DD Training Resources

**DD Training Resources provides information, resources, and training that support individuals with intellectual and developmental disabilities and their families.**

**Topics include accessing services, navigating systems, individual rights, advocacy tools, and finding resources in the community.**

**[ddtrainingresources.org](https://ddtrainingresources.org)**



*John King with volunteers (L-R) Volunteer and Co-Bike Camp Director Vicki Walters, John King, Bike Camp Director Karen Weidner, Camden County College security guard, and Camden County Public Works volunteer Stephen Bowerman.*