

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 4, 2020



Dylan Gano (L), a direct support professional, spends some quality time outdoors with Josh, a resident.

Balancing Risk During a Pandemic

COMMUNITY INNOVATION PROJECTS CIP

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Developmental Disabilities'

Community Innovation Projects (CIP)

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designed to bring about meaningful
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- Create and strengthen relationships with local associations and groups.
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- Have a plan for sharing successful practices.
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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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Dylan Gano, a direct support professional and Josh, a resident
Photo by Shaun Reilly

18 REOPENING CONGREGATE CARE, DAY PROGRAMS, AND LONG-TERM CARE FOR PEOPLE WITH DISABILITIES

Although COVID-19 cases are still occurring in New Jersey's developmental centers (DCs), the rate of infection had slowed down. As of October 18, the total number of cases was 1,095 and the total number of deaths was 40.

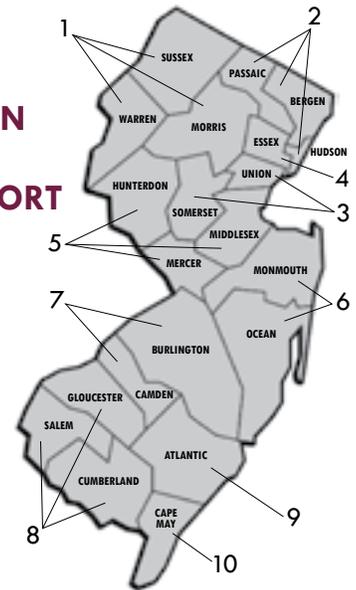


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During this global pandemic several readers discovered new hobbies or gained an appreciation for the little things. Several readers shared how they found peace during difficult times.



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During the evolution of *People & Families* magazine many dedicated professionals have remained behind the scenes—until now—writing, photographing, designing and printing a very professional and meaningful publication.

Thriving In Spite of The COVID-19 Crisis



Who could have imagined that we'd still be knee-deep in the throes of a global pandemic for almost a year? But we have—and we continue to press on!

In this issue of *People & Families* magazine we introduce NJCDD Committee Updates. A new section highlighting the contin-

ued work of the Council and its members. This initial segment highlights work on our new 5 Year Strategic Plan, the NACDD State Budget Crisis Taskforce, emergency funding, and other key initiatives.

I am particularly thrilled to announce the formation of the New Jersey Legislative Disability Caucus. NJCDD led the formation of this Caucus with collaborative community organizations. We were joined by Senate President Steve Sweeney, Assembly Majority Leader Lou Greenwald, Senate Republican Leader Tom Kean, and 26 other key founding legislative leaders, as well as self-advocates from the state's leading disability groups, to launch this historic bipartisan legislative caucus. We are now one of eight states to have a disability caucus.

When developing legislation, it is essential to follow the motto of the United Nations' Convention on the Right of Persons with Disabilities: **"Nothing about us, without us"**. People with disabilities are the ones who can better advise political leaders how pending legislation could impact their lives and the lives of their families.

I am confident that this Legislative Caucus will lead to a better New Jersey for individuals with disabilities and their families.

In this issue, we continue our COVID-19 theme by shedding some light on the impact of this potentially deadly virus, and sharing efforts to reopen in the midst of continued health risks. We also attempt to put an encouraging spin on this current health crisis by sharing positive pandemic passions which have come out of this disaster. Readers share their own COVID "Silver Lining" in order to inspire others to do the same.

For me personally, I've enjoyed forging stronger bonds with individuals, families, organizations, and political leaders to continue to move the needle towards better lives for people with disabilities and their loved ones.

While we are in the midst of another holiday season, I want to give sincere thanks to everyone who continues to press on during the most difficult circumstances. We all have our own struggles, yet your resilience and steadfast advocacy remains strong and encouraging.

In closing, I want to particularly acknowledge the outstanding work of the *People & Families* production team. We are fortunate to have a well-seasoned professional team of writers, an inspiring photographer, and an impressive design and printing team who help to tell our story with compelling stories and images.

Happy Holidays
Sincerely,

A handwritten signature in cursive script that reads "Mercedes Witowsky".

Mercedes Witowsky
Executive Director
New Jersey Council on
Developmental Disabilities



NJCDD COMMITTEE UPDATES

The New Jersey Council on Developmental Disabilities (NJCDD) is authorized under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (The DD Act), P.L. 106-402 and New Jersey Administrative Code P.L. 1979, Chapter 103.

The purpose of the NJCDD is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of life through culturally competent programs.

Council members include public members, representatives of state agencies and federally mandated members with a majority of members (60 percent) who are individuals with developmental disabilities or a family member of an individual with developmental disabilities.

The Council conducts four public meetings each year. The Council's Executive Committee meets throughout the year to handle matters concerning the Council when it is not possible for the full Council to meet and monitor the Council's Standing and Ad Hoc Committees.

The Council's standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee. Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy Committee. The Ad

Hoc Committee on Equal Access is within the State Plan Committee. The following is a snapshot of some of the committee highlights.

Executive Committee

Paul Blaustein serves as Chair of the NJCDD Executive Committee. The Committee shall act on behalf of the full Council in all matters when it is not possible for the full Council to meet. The Executive Committee performs the following duties:

- Assures ongoing policies and procedures are in place and implemented consistently within Council bylaws and State and Federal mandates.
- Oversees the Council's administrative and programmatic budgets
- Reports to the Council on the above activities.
- Monitors and supervises the Council's Standing and Ad Hoc Committees.

The Executive Committee welcomes Sarah Aziz as the newest NJCDD member. The committee thanks Governor Murphy and the State Senate for completing Sarah's nomination, confirmation and final appointment. The committee encourages the Senate to act on three additional Gubernatorial nominations. These exceptional individuals would add needed diversity, experience and expertise to the Council.

The Executive Committee authorized a second round of funding to provide equipment, such as hand held and computer devices. This equipment will enable individuals confined during the pandemic, to communicate with family and friends, participate in on-line therapies, day programming and recreation, access telemedicine, and maintain contact with their community and their activities. The committee appreciates the excellent work done by the executive director with the assistance of The Arc of NJ to establish and implement this essential funding opportunity.

NJCDD and the Health & Wellness Sub-committee will collaborate with the Statewide Family Support Council's Health & Safety Sub-committee. The collaboration will provide funding and staff support to implement best practices to ensure the health and well-being of individuals receiving services in DHS licensed residential facilities. Self-advocates, family advocates, state agencies, out-of-state and in-state providers and other experts will be recruited to work towards this critical task.

State Plan Committee

Helen Steinberg is the Chair of the NJCDD State Plan Committee. The role of the State Plan Committee is to manage federal requirements related to the development and implementation of the Council's Five-Year Plan. The Council has engaged the services of Considine Communications Strategies (CCS) to facilitate the development of its 2022-2026 Five-Year Plan. CCS is ensuring that the plan is being developed in compliance with the requirements of the DD Act and will include:

- Comprehensive Review and Analysis
- Plan Goals
- Assurances
- Public Input and Review
- Consultation and Designated State Agencies

Currently we are in Phase III: May-January, Development of Plan: "Envisioning the Future". The State Plan Committee has conducted a variety of public input activities as the Five-Year Plan is drafted. Workgroups have met over the past few months to include:

- Special Education, Healthcare/Wellness/Safety—discussing barriers, including policy practice, funding, to services/opportunities for innovation, cross cutting issues, priorities, and activities
- Employment, Transition, Transportation—Review data and public input, group discussion, personal experiences and perspectives
- Ad Hoc Committee to Ensure Equal Access to DD Services with Council member Safiyyah Muhammed as Chair to look at recommendations to include in the 5-Year Plan on targeted disparities

CCS is currently reviewing all the data (research data, survey, public comment, focus groups, reports) to look for threads, themes and trends. This will be reported to the Council in January at a Five-Year Planning meeting special retreat to finalize a draft of the Plan that will then be distributed for public comment.

Grants Committee

Kevin Nunez is the Chair of the Grants Committee. The role of the Grants Committee is to oversee the development of funding announcements that align with the Council's Five-Year Plan goals, objectives and activities. The Grants Committee reads all responses to funding announcements and makes recommendation to the full Council for funding and continued funding based on grantee performance.

This year, the Grants Committee focused attention on the significant challenges imposed by the Public Health Emergency related to COVID-19. The Grants Committee recommended release of Emergency Funding applications in an effort to help get people with developmental disabilities what they needed during the pandemic.

Since March 2020, the NJCDD authorized approximately \$450,000 in emergency spending for grants up to \$500 per person. Nearly 1200 applications were submitted, of which approximately 900 applications were approved for funding providing some form of assistance to nearly 3000 individuals with developmental disabilities. To help spread the support as quickly as possible, NJCDD enlisted the assistance of the Arc of New Jersey by amending a current contract. The Arc

of NJ successfully processed the applications and funding awards and, in some instances, initiated the purchases.

Funding was given for such items as hand-held electronic devices, art supplies, music supplies, Internet access and exercise equipment. Funding was provided for individuals of all ages, living in all parts of the state, from rural to urban. Items were reimbursed after being purchased online and shipped to the families.

Certain technology such as electronic devices helps to maintain a connection to health professionals, information, education, family, friends, and peers. Support groups, local, state, and national advocacy groups, virtual classes, and educational sessions are available and continue to be developed to assist people in finding alternatives to typical face-to-face activities.

The Grants Committee continues to monitor current funding awards and deliverables. In addition, grantees will resume providing in person updates at public meetings.

Public Policy Committee

Kara Kushnir is the Chair of the Public Policy Committee. Andrew McGeady is the NJCDD Vice-Chair of the Public Policy Committee. The role of the Public Policy Committee is to review legislation and public policy materials made available by Council staff and other sources. After discussing these materials, the Public Policy Committee recommends positions and follow up actions.

NJCDD Public Policy Coordinator has been active since June as a member of the National Association of Councils on Developmental Disabilities (NACDD) State Budget Crisis Taskforce to systemically work to avert state budget cuts due to the pandemic. The success of the “No Cuts” effort in NJ was recognized and highlighted in a webinar presentation to NACDD nationwide in early October.

The NJ Legislative Disability Caucus, spearheaded by NJCDD along with other disability organizations has been developed with Association Business Solutions (ABS) progressed steadily, with a kickoff announcement slated for December 1, 2020. Senate President Sweeney will chair this Caucus and numerous bipartisan legislators and

advocates will participate. Quarterly Caucus virtual meetings will be held during 2021. These meetings will provide a “virtual place at the table” for people with disabilities by providing legislators with valuable input while furthering dialogue.

On October 22, 2020, NJCDD provided testimony to a Special Hearing of the Assembly Human Services Committee on abuse and neglect in group homes. The seriousness of this problem and the barriers to safety and community life that people with disabilities face is well-documented. It deserves decisive and immediate action. Government must continue to recognize and guarantee the civil and human rights of individuals with intellectual and developmental disabilities. This includes advancing laws and regulations that provide individuals with the information, skills, opportunities, and supports to pursue meaningful, fulfilling and productive lives and to live free of abuse, neglect, financial and sexual exploitation.

SUBCOMMITTEE ON CHILDREN AND YOUTH

Peg Kinsell is the Chair of the NJCDD Subcommittee on Children and Youth. The NJCDD subcommittee on Children and Youth (C&Y), comprised of more than a dozen parents, advocates, community leaders, educators and Council members, focuses on issues that affect those under the age of 21 and their families.

Access to Family Support Services

The C&Y subcommittee is addressing issues and barriers as they relate to Children’s System of Care (CSoc), and the challenges families face in accessing support services they need. Leaders from the Department of Children and Families (DCF) joined the committee for a discussion of Family Support and crisis services during COVID. The Subcommittee is looking at ways to ease the process for applying for and accessing services, and helping to ensure that they agencies that serve children, including local school districts (LEAs) are more aware of family support services through DCF. The C&Y committee has formed a workgroup to review regulatory language to compare it to the enabling Family Support Act from 1993. The goal is to identify any regulatory barriers or inconsistencies that might be making

it harder for families to access services.

The subcommittee continues to explore ways to help families through the crisis; is following state and federal policy developments; and is sharing ideas and strategies. This year, the C&Y committee has focused on Extended School Year (ESY) services; safety issues for re-opening special education; and access to supplemental and compensatory services for students of transition age, many of whom are missing vital community learning opportunities during COVID.

Adequacy and availability of direct advocacy supports

Many families need direct advocacy support in the IEP process. The NJ Supreme court has recently issued an opinion that limits the role of non-attorney advocates in special education IEP meetings, including those trained through the Council-funded SEVA grant. The C&Y subcommittee has guided the Council in the development of comments to the court to express opposition for this opinion, urging that non-attorney advocate remain a resource to families.

2021 State Budget

The C&Y subcommittee reviewed and discussed the 2021 state budget action needed on state budget as it related to children and youth.

Looking Ahead

The C&Y subcommittee will explore ways in which racial, cultural and language differences affect access and outcomes in special education. They will revisit disproportionality and data as it related to school to prison, discipline issues, placement, restraint and seclusion, school resource officers.

They will also continue to monitor issues around the seclusion and restraint of students with disabilities in school, residential and other settings.

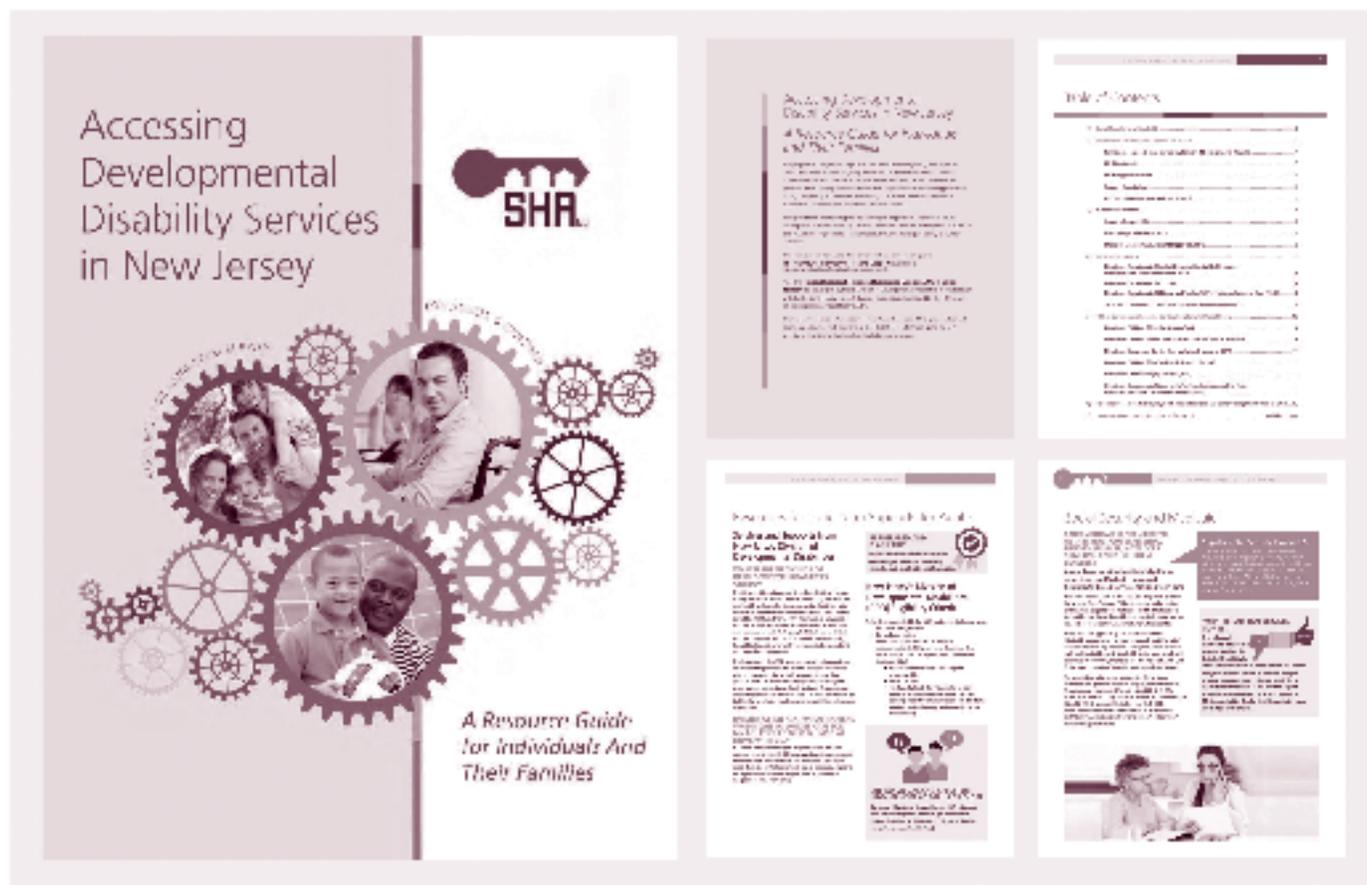
With the pandemic, Initiatives around School Safety as it Relates to Students with Disabilities have been sidelines While bipartisan legislation was introduced in both houses in the New Jersey Legislature to advance the goals and recommendation in the report, there has been no movement since March 2020. **P&F**

The banner features a dark purple background with a large white speech bubble on the left containing the text "Disability in Focus". To the right of the speech bubble is the logo for "The New Jersey Council on Developmental Disabilities". Below the logo are three buttons: "Presenting Facts", "Sharing Views", and "Starting Conversations". The bottom section of the banner includes an illustration of several hands holding up a megaphone, with the text "Visit the NJCDD's Blog, **Disability in Focus** to get the latest news and views from around the state and across the country about our developmental disabilities communities. Join the conversation by sharing your own views on topics we discuss." and a call to action: "We Can't Wait to Hear From You! Visit us at www.njcdd.org".



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>





SEARCH Day Program in Monmouth County restructured the school day to minimize risk of transmission of infection, and to maximize in-person student learning opportunities. Here, the parking lot is converted to outdoor learning spaces. —Photo from SEARCH Day Program

Balancing Risk During a Pandemic

By Brenda Considine

‘Zoom fatigue’, hand sanitizer, and face-coverings not-withstanding, people everywhere are finding new routines amidst the chaos caused by COVID-19.

Ten months into the pandemic, this is also true for children and adults with intellectual and developmental disabilities, their families and those who provide supports and services to them.

At SEARCH Day Program, a private school in Monmouth County serving those with autism, students are back on campus. The school closed to in-person learning on March 17, but the very next day, leaders there started working on a reopening plan. Four months later, on July 13, students returned to campus and continue to have the option for in-person learning ever since.

“We could never have been ready to reopen when we did if we had not started planning right away,” said Kathy Solana, executive director. “It gave us the time we needed to prepare our staff, our families, our students, and our sending districts.”

The word “prepare” is an understatement. Solana and her staff, with input from stakeholders and public health officials, carefully revamped every aspect of the school day. From the physical space, to the program, and instruction itself, every school protocol and procedure was re-examined in light of COVID-19 precautions.

The school grouped students and staff into small cohorts to minimize contact with others. They used outdoor spaces and classrooms in new ways. They created an individual school schedule for each student. They also doubled their custodial staff to ensure that surfaces and classrooms were wiped down and sanitized throughout the day.

Then, they spent hundreds of hours in 1:1 and small group discussions with staff, families and school districts explaining the plan, testing, and running through protocols. And all of

this, while serving students who are learning remotely at home.

According to Mike Carpino, BCBA, the school’s principal, the real effort happened when the rubber hit the road—in the classrooms with students.

“We needed to figure out how to clean and sanitize materials, transfer student materials, and change over for a varying set of in-person students every day,” he said.

The preparation and hard work paid off.

“When the children arrive and walk into school, under those face coverings, there are smiles. They are excited to be at school, and we have a faculty that is well prepared to safely implement a school day,” Carpino said.

According to Solana, students are doing well and following safety protocols. “In spite of all the predictions, none of our students experienced regression, and most of our students are able to wear a mask—many arrived on the first day wearing one,” adding, “Even transition-aged students are getting meaningful services aligned with their IEP goals.”

While community-based learning is off limits for now, students get virtual and simulated job interviews and community trips.

There have been some surprising silver linings.

Before the pandemic, school leaders were not well-versed in remote learning, but in short order, they learned what works for students and families. They also noticed increased communication with parents through emails, telephone contacts, and video consultation. While the school always made communication with families and districts a priority, COVID-19 raised the bar.

“All of our faculty now enjoy daily communication with families and detailed logs for districts. Staff have been able to more completely share a picture of how instruction and therapy is conducted, and how to help children learn at home. Parents are learning how to use those strategies to help students learn at home; and help them feel empowered to have a positive and effective impact on their children’s lives,” she concluded.

It has not been so easy for other students and families.

Twelve-year-old Layla Aziz has autism. The middle of three children, Layla typically attends a self-contained classroom for students with multiple disabilities operated by her local Middlesex County school district., But, for the last nine months, she has been at home. According to her mother, Sarah Aziz, an active advocate and member of the NJCDD Subcommittee on Children and Youth, remote learning has been “devastating” for Layla.

“I am not a surrogate for her teachers,” said Aziz. “My other children will be fine, but remote learning is not working for Layla. She needs to be in school, she needs one-to-one.”

Aziz, whose career as a CPA was put on hold to care for her children, notes that her daughter has shown regression in reading and math, as well as regression in self-regulation “We are seeing a lot more meltdowns now,” she said. “I think she has lost a year’s worth of learning. For some students, I think they should stay in school an extra year – until age 22. There is no other way to make this up,” she added.

Aziz says that schools and teachers are doing the best they can. “In-person, it is hard enough, but remote learning for a child like Layla just isn’t working.”

Family Support Efforts

Aziz and her family were recently approved by the Children’s System of Care within the Department of Children and Families for family support ser-



Kitty (L) a resident at one of The Arc of Cape May’s programs, joins Assistant Supervisor, Denise Fessler (r) in the garden last summer. —Photo from Shaun Reilly

vices. “We need the help here. It is a very challenging situation for us,” she said. But so far, that help has not come.

With children at home, many families are stressed and isolated from traditional care and family support. It would seem that services through the Department of Children and Families are needed more than ever so it is surprising that data show dramatically decreased call volume to PerformCare when compared year-to-year. In April, at the peak of the pandemic in New Jersey, calls were less than half what they were in 2019. There was a 72 percent decrease in emergency mobile response dispatches. .

According to Kyoko Coco, family support coordinator at the New Jersey Council on Developmental Disabilities the decrease may have to do with the fact that there are so few family support services available to help families with children under 21 right now.

“There has been no afterschool programming since March. I think families need help, but they are not asking for respite care because they want

to limit the risk of exposure from others,” she suggested. “They simply don’t want people in their home.”

For adults with I/DD living with parents, there is some good news. The Division of Developmental Disabilities (DDD) recently lifted restrictions on paid overtime, so a single staff person can be the caregiver for many days. “This helps families because it reduces exposure by reducing the number of different caregivers a family needs to use,” said Coco.

At the beginning of the pandemic, DDD began allowing parents to be paid as caregivers. While this allows families to use their budget, and directs resources to parents, it does little to provide a break for stressed parents.

Balancing the Risk

The CDC has advised Americans to keep a “social distance” of six feet, wash hands frequently, and wear a face covering to stay safe. But some people, including those with developmental disabilities are at greater risk than others.

The Annals of Internal Medicine reported that people with Down syndrome are four times more likely than others to be hospitalized, and 10 times more likely to die from the virus. Another report, using data from New Jersey and seven other states, found that people with I/DD were no more likely than others to contract the coronavirus, but were nearly twice as likely to die than others (12.3 percent of those with the disabilities vs. 6.7 percent of virus patients in the general population).

To help mitigate risk, state government leaders developed policies designed to keep people safe and healthy, but as engaged in ‘normal life’ as possible. DDD developed and maintains a dashboard tracking COVID-19 among those receiving DDD services. At this writing, 936 individuals have tested positive, with nearly 10 percent dying from the

virus. Developmental Centers (DC) and nursing homes have been especially hard hit. Of 1,238 people living in New Jersey’s DCs, 468 have tested positive for the virus and nearly 40 have died. Of the 4,300 staff, nearly 600 have tested positive.

Community providers have been hard hit too, not only with COVID-19, but also with the cost of efforts to keep residents and staff safe. This fall, the Department of Human Services announced coronavirus relief funding for community providers. Using federal funds, the new program will help providers remain open and accessible during the pandemic by reimbursing for the added costs for things like PPE and enhanced cleaning.

Early on, family visits for those living in congregate settings were prohibited, but in June, DDD provided updated guidance. Emphasizing short outdoor visits, social distancing, mandatory face coverings and a careful screening, families were once again allowed to visit loved ones.

Layla Aziz, 12 yrs. old with her mother Sarah, working with Layla’s iPad during the Covid-19 pandemic.



Housing and Jobs

At The Arc of Cape May County, things have not been easy. The nonprofit agency provides residential services and support, day and recreation services, and supported employment to more than 150 individuals with I/DD in one of the most rural areas in the state. Their popular thrift shop was shut down in March when the quarantine began. This June, with safety plans in place, the shop reopened for business.

“Individuals are back to work, and for those who did not feel ready, we found other opportunities,” said Leslie Long, executive director. “With para transit now limited to medical appointments, and public transportation not a safe option, we have turned to staff and administrative leaders to drive people to work and community opportunities.”

The day program is open for virtual services, and while all of the adults at The Arc of Cape May are now connected with devices and internet services, Long says remote day programming is a challenge.

“The attention span for any of us working on the computer is limited. Even those who love it get bored. It is hard to maintain attention,” she said. And while she is thankful that her agency has not had any cases of COVID-19, it has been a daily challenge to keep residents living in the agency’s group homes safe.

“We take quarantine rules very seriously, so if staff travel out of state, they are off the shift for 14 days. We have not bent the rules at all, and when needed, administrative staff have stepped in to provide care,” said Long.

Long and her staff have had to get their own PPE. “We were not considered ‘essential workers’ even though, clearly, we are. Our staff had to fight for PPE with the county,” she added.

“What has gotten us through this is that our frontline staff, the individuals we serve, and our families have been amazing. We were united—our shared priority was safety,” she said.



Students at SEARCH Day Program in Monmouth County have been back to in-person learning since July. Students are socially distant and taught to use safety protocols.

Bridging the Tech Divide

Early in the pandemic, NJCDD directed some of its resources to help get technology into the hands of people with disabilities. Electronic devices can help individuals with I/DD make connections for health and wellness, advocacy engagement and for education and socialization.

Among those who applied was CC, a resident of The Arc of Cape May County, who requested funding to purchase a karaoke machine.

“It seems like such a small thing, but it made such a difference to her. It got her up, and connected her to something she loves,” said Long. “It made her feel connected to the other people she

lives with and introduced some fun—and safe—recreation into their lives.”

Psychiatric and Behavioral Needs Unmet

Long has found the need for enhanced psychiatric services.

“Living in a rural area where mental health services are over an hour away, and with an increase in psychiatric issues in younger participants, people are going to the ER when they need help, and then being transported for three hours to Trinitas Hospital in Essex County because we simply can’t meet the demand,” she said.

“Our clinical staff is helping but we need a psychiatrist to serve those with comorbid psychiatric issues so they can be treated safely at home,” she said. “We have applied for a grant to get access to a psychiatrist via telehealth which will certainly help.”

Medical and Hospital Considerations

In mid-May, Judith Persichilli, commissioner, Department of Health (DOH) issued a memo specifically requiring New Jersey hospitals to allow a support person to accompany a patient with

a disability or psychiatric condition in both the ER and the hospital regardless of the reason for hospitalization. It has been a big help to families like Barbara Cook’s (pseudonym).

In June, just as COVID-19 lock downs were lifting, Cook learned that her 26-year-old son with an autism spectrum disorder had advanced cancer. His world was tossed upside down, as surgery and treatment began within days.

“I had always gone with him to medical appointments and was shocked to learn that COVID-19 rules prevented any guests from even going into the building,” she said.

Initially, hospital staff declined Cook’s request to stay with her son through chemo and after surgery, but once she provided a copy of the DOH memo and proof of her son’s DDD eligibility, they allowed her and her husband to take turns at all his appointments.

“It was a huge help to be able to be there at his bedside, not only for him, but for the nurses and doctors as well,” she said. “Good public policy has to consider the whole person, in this case, it really made a difference,” she concluded. **P&F**



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Reopening Congregate Care, Day Programs, and Long-Term Care for People with Disabilities

by Maryann B. Hunsberger



DDD Congregate Care

Although COVID-19 cases are still occurring in New Jersey's developmental centers (DCs), the rate of infection had slowed down. As of June 21, all five of New Jersey's developmental centers had outbreaks. From March to June 21, 880 DC residents and staff had been infected with COVID-19, and 33 residents and staff had died. As of October 18, the total number of cases was 1,095 and the total number of deaths was 40.

Jonathan Seifried, assistant commissioner of the Division of Developmental Disabilities (DDD), said that for individuals who reside in any of the five developmental centers operated by DDD, prudent actions continue to be taken to mitigate the risk of COVID-19 infection.

"All decisions are based on protecting resident and staff health and safety. Nothing is more important than the health and safety of individuals, their families and staff," said Seifried. "The centers closely follow New Jersey Department of Health guidelines. This includes the ability of families and friends to engage in virtual visits, as well as outdoor and indoor visitation under certain circumstances. Additionally, community settings remain curtailed due to the congregate nature of developmental center settings."

Outdoor visits with social distancing began at DCs on June 21, and indoor visits were allowed as of July 26. Social distancing and use of personal protective equipment (PPE) are required.

The COVID-19 Response Plan for New Jersey Developmental Centers of October 9, 2020 outlines the steps taken to mitigate outbreaks:

- Each center has established a COVID-19 Committee to both manage all aspects of the COVID-19 response and to support the broader work of existing Infection Control Committees;
- All residents and staff have been reeducated on hand hygiene, including hand hygiene after contact with respiratory secretions, with regular reinforcement;
- All staff has been reeducated on cleaning and disinfection procedures, with regular reinforcement;
- Enhanced and more frequent cleaning of highly trafficked areas and surfaces;
- Reinforcement of universal precautions and social distancing, to the extent practical based on person-centered needs;
- Adjustment of staffing patterns to ensure critical services are provided while reducing the number of individuals that pass through resident areas;
- Use of PPE throughout each center.

Michael Brower, managing attorney of Disability Rights New Jersey (DRNJ), the advocacy group monitoring New Jersey's DCs, said the general rule regarding visitation in DCs requires all locations to be infection free for 28 days before visitors can come inside. Any individual can meet

someone outside as long as they are infection free.

“What’s actually going on is pretty close in line with policy. They are doing a good job of sticking to their own policies. When the infection numbers were low, some visitors were coming inside, but a lot of visitors have switched back to virtual because people are getting sick. As the days get cold, sitting outdoors won’t be workable.”

Brower said residents aren’t restricted to their rooms. “They can move about the whole cottage. They try not to mix different cottages together in case someone is positive. Instead of moving around the campus to do activities, the staff is coming to the cottage to do the activities. They are even bringing jobs to the cottage. For some jobs, the work can be transported, like shredding. Some people are doing different jobs. So, instead of doing ground maintenance, you might switch to doing maintenance in your cottage.”

Seifried pointed out that residential providers have always been allowed to continue to plan home and community activities for individuals who live together, much as other households are doing during this time. He stressed that, “these activities must be consistent with the advice of public health authorities to avoid large gatherings or areas where groups of people congregate.”

Off campus travel has been restricted. Residents only go off campus for essential medical appointments. Some medical appointments are done onsite, and telemedicine is also used.

Group Homes

Brower said only a handful of complaints have come in from individuals or families regarding group homes. “These were mostly isolated cases of communications breakdowns or differences of opinions about how much precaution needs to be taken.”

Brower said visitation policies have been strictly adhered to by group home providers as outlined in Guidance for Residential Providers on Visits with Families and Friends dated July 23, 2020:

- Each participant must stay six feet apart from each person they do not reside with.
- Each participant must wear a face covering.
- After a visit in a space controlled by the provider concludes, the provider must clean and disinfect all areas and surfaces that

visitors were in contact with.

- No resident, staff or visitors can be in close contact with someone who recently tested positive for COVID-19.
- All participants are required to monitor themselves for signs and symptoms of COVID-19 for at least 14 days after the visit.

A few residents are back at day programs, according to Brower. Since most residents aren’t attending programs, group homes are getting an increased rate to do home activities for people who can’t attend day programs. Some group home providers have provided activities based on individual interests, such as interactive Zoom activities on gardening, along with movies and board games. They’ve also done backyard activities such as cornhole and badminton.

Seifried said, “We do hope the steps we’ve been able to take will have a positive impact on individuals and families, and that public health will continue to improve so we will be able to keep moving forward. No matter the situation going forward, everything will continue to be based on data, public health and the health and safety of individuals and staff.”

Day Programs

So much can change in one month.

During February 2020 routines were the norm for families who have adult children with disabilities. Many adult children living at home or in group homes went to day programs or worked at jobs. Some who lived in developmental centers or long-term care centers (LTCs) did activities, went on trips or spent time with visitors.

Suddenly in March, with COVID-19 moving quickly through our state, everything stopped. Day programs closed. Places of employment shut down. Parents who normally worked had to stay home with their children. Developmental centers and LTCs stopped group activities and allowing visitors. Family members couldn’t even see their adult children. Nobody knew what to do and chaos set in.

Individuals living at home and in group homes felt lost as day programs around the state closed in March. The state looked for immediate solutions. Mercedes Witowsky, executive director

of the NJ Council on Developmental Disabilities (NJCDD), said the state granted flexibility so parents could become self-directed employees for their children. However, staying home and becoming paid caregivers brought about a number of challenges.

“Some parents we heard from said they were having trouble meeting their own financial obligations. Some lost health insurance as a result of losing employment. Some parents were physically, emotionally or technically unable to meet their children’s needs. Some individuals who had no behavioral support needs developed behavioral support needs because of the pandemic. But, behavioral supports weren’t available. Parents felt that they became the physical therapist, occupational therapist and personal care attendant all in one. Parents didn’t feel properly trained and watched their children lose skills and lack motivation. We’ve seen social isolation that is difficult to combat.”

Witowsky served on the Department of Human Services’ (DHS) Day Program Reopening Committee to assess the situation and make recommendations the state could use in their Congregate Day Program Reopening Requirements document. In order to plan for the future, the committee researched what was happening while in-person programs were closed. “We looked at how day programs were connecting with their participants and continuing to access some remote services. Some day programs set up virtual classes and ways people could participate from home. Some dropped off materials that people could use. Some sent staffing to homes if individuals were willing.”

The state included communication to individuals and families on what the risks of exposure to indoor activities were. This gave families the opportunity to evaluate whether the risk of attending day programs would be in the individual’s best interest based on their circumstances. “It’s a mixed bag as to how families feel. We did a survey of families asking how they felt about reopening and what considerations they’d take into account. It was all over the map. Some families couldn’t wait. Some wouldn’t agree to send their loved one back until a well-established vaccine was in use.”

The individual, their family and the day program then completed an Individual Needs and Risk Assessment together. “This would determine person-by-person how they would fit into the day program’s reopening plan while determining their medical, behavioral and transportation needs together. In some cases, the families wanted their loved one to return, but the day program found it too risky. Or the program wanted them to return, but the person and family found it too risky. They had to come to a common place.”

Reopening during a pandemic meant logistics became complicated. Day programs cannot open at more than 25 percent of their capacity. No more than 15 people can group together. Day programs typically arrange transportation, but state protocols meant people needed to be separated. A van that fit seven people would only fit two with distancing. The providers were given flexibility in how they would structure their day to comply with the state parameters. Some staggered days to give more people the opportunity to attend part-time. But, this wouldn’t work for all. “Some day programs said they couldn’t bring back only a few people and decided to continue using remote services and educational opportunities.”

The Division of Developmental Disabilities (DDD) created a Facility Readiness Tool (Tool) to determine preparedness around things like screening and admittance, face coverings, personal protective equipment and promoting healthy hygiene practices. This allowed the state to evaluate the planned day program protocols. To reopen, programs must determine if they are ready to do everything in the Tool or if they still need to address certain areas. After reviewing the Tool, they must attest that they meet all the requirements.

“The Tool encompassed giving direction to the day program facility to explain what they would need to reopen. How would they screen and admit people each day? What did the facility need in terms of physical considerations, like hand sanitizing stations, separation of groups, checking heating and ventilation systems, operational layout, personal protective equipment (PPE), cleaning and sanitizing supplies? The facility had to evaluate what transportation

they could offer and how they would sanitize the vehicles.”

The committee also made recommendations around training staff to adhere to safety precautions, such as using PPE, storing backpacks or lunch pails, cleaning electronics or chairs and tables and other potential areas of exposure. “So many details are going into how to configure things. The staff has to learn how to do all of this.”

About 70 day programs attested mid-October that they could and would reopen. “Not all immediately opened. Since the programs had been closed for several months, much planning and work goes into reopening. Just like any other business, they had to follow guidelines set by the state as to how they would meet those requirements.”

Witowsky said they haven’t heard from slightly over half of the state’s 350 day programs. “We don’t know if all will ever reopen. Families want to know what the future of day services will be and what to expect as we get closer to a new normal. We have an obligation to explore and give options to families. Some programs are doing hybrid models. Some never even offered remote services, but now they will. The state is offering partial funding for that. Every business has considerations as to how to remain solvent during an emergency like this. Just as some businesses haven’t been able to survive the impact of COVID-19, the fear exists that this could happen to some day programs.”

Witowsky hopes the Council, together with DDD and the Division of Vocational Rehabilitation Services (DVRS) will help people explore other options, especially for the day programs that don’t reopen.

However, bright spots offer hope for the future. Witowsky said she enjoyed hearing parents talking about how they didn’t think their children would manage, but they found new opportunities. “Some people will never go back to residential programs or day programs because they have experienced and learned things that make life better. They are going for walks, growing plants, sitting through yoga sessions on Zoom. We’re hoping that as caregivers get to know their family

member in a different way, they can find and encourage new opportunities.”

Ann Martinelli of Colts Neck found new opportunities for her son, Joe. Though he works with a self-directed budget and has never gone to a day program, the pandemic still required him to find new ways to spend his days. Joe, 36, previously volunteered at an assisted living facility and at Habitat Humanity ReStore, went out to eat with friends and took dance classes.

His mother said he is now doing things he never did before. “He never was big on exercising or going to a park. Due to COVID-19, his direct support person, Manny, encouraged him to go outside. They started going to a local track to walk. He got more comfortable and they started playing music and exercising at the park. They also would watch football and soccer teams getting ready for the fall season.”

Joe also switched to online physical and occupational therapy twice a week. “They teach him range-of-motion and stretching exercises through an iPad and watch how he does them sitting in his chair or lying in his bed.”

He also does virtual dance classes now. “I would have never thought he’d be interested in doing it online. If you had asked me a year ago if I thought this would work, I’d have said no. But, it works.”

Long-Term Care

The office of Long-Term Care (LTC) Ombudsman Laurie Brewer is investigating more than 50 complaints because families say that many LTCs are not complying with Department of Health (DOH) Commissioner Judith M. Persichilli’s August 2020 memo permitting residents to have limited indoor visits. Adults of various ages with intellectual and developmental disabilities (I/DD) reside in our state’s LTCs, which include nursing homes. According to the 2016 RISP (Residential Information Systems Project), a project within the University of Minnesota College of Education and Human Development, 856 New Jersey residents with I/DD reside in nursing facilities.

The DOH memo outlines the requirements for initiating a phased reopening of LTCs. All facilities were at phase 0 when the memo was released. To reach each of the next three phases,

providers were asked to attest to having accomplished a number of critical tasks in order to gradually reopen their facilities to visitors and also to afford residents greater mobility within the facility [such as communal dining, communal activity with social distancing].

In order to move out of Phase 0, where every LTC starts, facilities must prove that they have:

- A stockpile of PPE
- Adequate testing capacity
- An outbreak plan including emergency staffing plans
- A comprehensive plan to communicate to residents, staff and family members when they have a positive test.

They must also prove that they have gone 28 days without a positive COVID-19 test. It is also requires an infectious disease specialist to be on staff or under contract. Each facility is in a different phase depending on where they are with outbreaks and attestations.

- As of October 15, 2020, 150 LTCs in the state had active outbreaks.
- 376 LTCs were still at phase 0;
- 141 LTCs were in phase 1. Limited activities may be conducted for COVID-19 negative and asymptomatic or COVID-19 recovered residents only in their small group;
- 132 LTCs were in phase 2. Indoor visitation by appointment is allowed. Limit communal dining to COVID-19 negative and asymptomatic or COVID-19 recovered residents only;
- None had reached phase 3. Allow entry of volunteers. Resume group activities;
- All phases are based on Governor Phil Murphy's *Road Back to Recovery* document dated May 18, 2020.

With more than 7,000 LTC residents and staff deaths from COVID-19, Brewer said that the level of caution seen among LTC providers isn't necessarily unwarranted. "New cases are still happening. Some facilities are still coming out of the outbreak. It's a moving target. There is a tremendous amount of anxiety out there among staff, residents, family members and other caregivers. The experience of this past spring was traumatizing

for everyone involved. Because New Jersey was hit so hard and so early in this pandemic, the state has, by necessity, had to be more restrictive than what the federal government recommends."

Government officials feel they have reasons for their actions. During a routine COVID-19 briefing, Governor Phil Murphy said, "We know we are stricter than the federal guidelines. That's not necessarily a bad thing."

Commissioner Persichilli stated, "We still have 150 active outbreaks in our nursing homes. Although they're small, we are catching them more quickly and mitigating and containing the spread; we still believe we have to be more vigilant because of widescale spread throughout the state."

But, Brewer feels the state and nursing home administrators must do a better job of finding balance. "It is critical that a balance be struck between caution and the need to reduce social isolation and loneliness among LTC residents. Thousands of people have been mostly in their rooms for more than seven months now. Some people have had outdoor visits and an even smaller number have had indoor visits from their families. Some facilities are just now beginning to allow communal dining and communal activities."

As for the residents who are still isolated, Brewer said, "I know that there are staff members in these facilities who work very hard to reduce the social isolation among residents. Recreation and activities staff are developing new and innovative ways to conduct activities with residents who cannot leave their rooms."

One administrator held zoom meetings with the residents every afternoon to update them on current events and COVID-19 numbers and would end with an inspirational quote or a joke. Hallway bingo was a success at many facilities. If possible, residents would sit in their doorway while recreation staff would stand in the hallway and call bingo numbers. If the resident was unable to leave their bed, staff would stand in the doorway of their room and call the numbers. If the resident won, they would ring their call bell. Mobile ice cream carts were also popular. And video calls to family, facilitated by staff, remained a favorite.

The Ombudsman is advocating for family members to resume at least weekly indoor

visits with proper PPE. Although visitation is restricted until phase 2, the DOH memo states that all residents may receive Essential Caregiver visitation [except for those that are in a 14-day quarantine period or positive for COVID-19]. “An Essential Caregiver can come at any time, once a week. They don’t have to wait 28 days after an outbreak. The facility must set up a time and conditions to make it work. If the person has a roommate, for instance, the visit probably has to be in another designated area. The visitor must wear PPE, but they don’t have to stay six feet away.”

Another special designation is a Compassionate Caregiver. These are not routine visits, but special circumstance visits. “A family member, friend or caregiver who actively engaged with a resident who has a serious decline in condition, or who has had a death in family and is not coping well may qualify for one of these visits.”

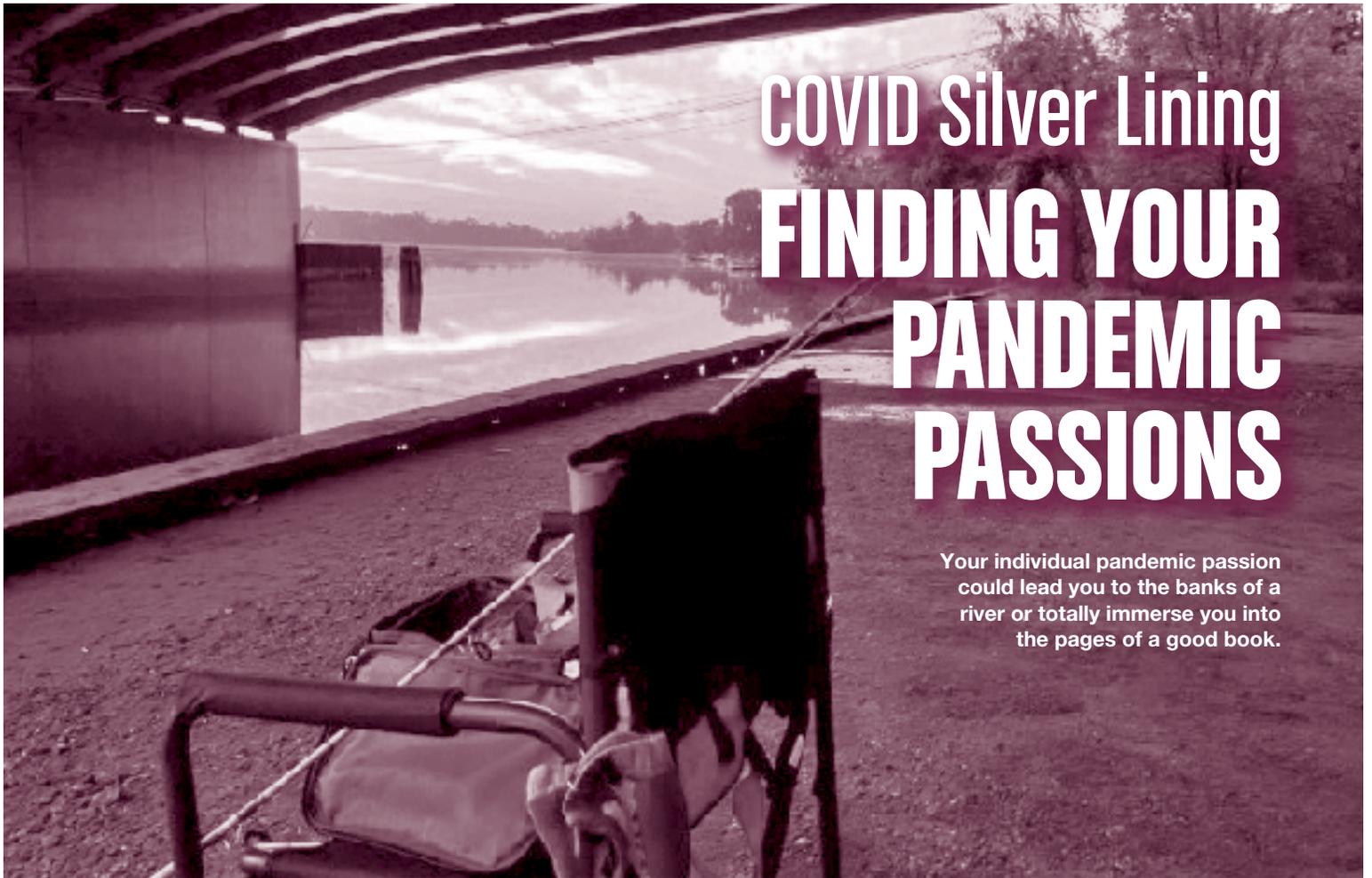
Neither the Essential Caregiver designation, nor the Compassionate Caregiver designation were created until five months after the quarantine started, when isolation was already a serious problem. Brewer said the main goal of these caregiver designations is to connect with loved ones, give them hope and reduce their isolation

and loneliness. “Loneliness and social isolation have severe negative effects on someone’s physical condition. This emotional support is critical to the residents’ wellbeing. The smiles on the faces of these residents seeing their families for the first time in months are heartwarming, but also heartbreaking.”

Yet, many families say they are still prevented from seeing their loved ones and given arbitrary reasons as to why. Some who have been designated as Essential Caregivers or Compassionate Caregivers have been denied visits anyway. So, families are advocating for greater access. Brewer’s office has been busy working to resolve these situations. “We make our case that the residents’ rights are being violated and the facility is out of compliance with the state mandate. We ask them to reconsider and try to resolve the situation to the best for the resident.”

Brewer said DOH will probably revise their guidelines based on federal recommendations and COVID-19 trends in the state. “Right now, the facilities are still operating under the DOH August 2020 Executive Order on reopening LTCs. I anticipate that there will be additional changes to this guidance as the week’s progress. The state could revise by the time this goes to print.” **P&F**

The image shows a screenshot of a newsletter sign-up form for the New Jersey Council on Developmental Disabilities (NJCDD). At the top left, it features the NJCDD logo and the text "New Jersey Council on Developmental Disabilities". The main heading is "Subscribe to our Advocacy in Action newsletter". Below this, it says "Your source for news and updates from the New Jersey Council on Developmental Disabilities". There is a text input field labeled "Your email:" and a "Submit" button. To the right of the form, there are three bullet points with speech bubble icons: "Keep up-to-date on NJCDD events and announcements", "Stay informed on important developmental disability news from around our state", and "Learn more about the NJCDD's programs for self-advocates and families, as well as new ways to participate". At the bottom left, there is a "Contact" section with the name "Gary L. Brown", the title "Communication Officer", and the email "gary.brown@njcdd.org".



COVID Silver Lining FINDING YOUR PANDEMIC PASSIONS

Your individual pandemic passion could lead you to the banks of a river or totally immerse you into the pages of a good book.

Editor's Note

There is no question that this pandemic continues to have a significant impact on all of our lives. Many of us continue to struggle with this new, but temporary reality.

My personal goal has always been to find the positive in any situation—no matter how daunting.

During this global pandemic I've been fortunate enough to discover a new and very peaceful passion: fishing. Before work I've enjoyed 2.5 mile walks before chewing on a premium cigar while casting my baited line into a lake during those peaceful pre-dawn hours.

So, I challenged our readers to share their pandemic passions in order to inspire others to do the same. Thank you for accepting the challenge and finding your silver lining!

With totally working from home, I have saved on dress clothes (purchase & maintenance), and can multitask during certain zoom meetings, as well as a long powerwalk each morning. Working totally from home has greatly decreased the wear and tear on my car, my body and my soul.

Because of the Pandemic I have been able to pick up some of my hobbies such as sewing and knitting.

Because of the Pandemic I have been working harder to stay connected with more people via text, zoom, calls, and cards.

Zinke McGeady, family advocate

My COVID silver lining is my family. They keep me alive and going like an Energizer Bunny. Having a wife and son is so important to me. I consider them a treasure. Together we make memories which last for a lifetime. We'll get through every battle either from a pandemic, natural disaster or sickness. Our faith will forever remain strong, no matter what.

Ryan Roy, self-advocate

My silver lining during the pandemic is that I've had more time to learn about the services and benefits I receive. I have also had the time and resources to find a singing teacher for private singing lessons and I'm about to start taking private acting classes too.

Julia Simko, self-advocate

Cooking was never my favorite activity but during this pandemic I have been cooking healthier meals daily for my husband and I. Sharing recipes with family and friends has expanded my love for a variety of foods.

*Pamela Brown, MSW
Vice President of Adult DD Services
Oaks Integrated Care*

Gratitude. Deep gratitude has sustained me through the pandemic. That my husband and I still have our jobs, and no one in my family has gotten sick. While I know so many people around me who have gotten sick, and died too. My son is also doing well. He is extra cranky due to missing some of his routines, but that's ok too.

Chris Peters, family advocate

My 19-year-old son Mikey has a dual diagnosis of both autism and Down syndrome. It certainly has been a challenging time with school completely stopping as well as a home ABA program and many activities he worked on vanished. I decided to get him some horseback riding lessons and he has found a new love!!

Peggy Romano, family advocate

Our family has been working to keep ourselves physically and emotionally strong, positive and healthy during this pandemic. My son, Abhishek and I have been cooking and taking nature walks together while enjoying some good weather.

Shukla Dey, family advocate

Living in a lake-front community during this pandemic has allowed me to slowdown and truly appreciate the scenery. I spend time breathing the fresh air and taking stock of life, my family, the future.

Dr. Marla E. Leen Ravin

The group home staff at YCS-Princeton has not only kept my son Michael safe but spent time with him and his iPad. Thanks to their commitment and dedication, Michael is attending to and enjoying multiple games and movies for an increasing amount of time. They are the best!

Cathy Tamburello, family advocate

When the pandemic hit and we were all staying home, I knew this was my time to start getting healthy because I couldn't use the excuse "If I only had more time, I could....." I started exercising using YouTube videos and searched on Pinterest for easy, healthy recipes. I am down 18 pounds, and I now realize that exercise helps not only reduce my waistline, but my stress levels as well!

*Erin Oleen Brambrick, M.Ed.
School Counselor, Student Assistance Coordinator
Cape May County Special Services School District*

The pandemic has been stressful and exhausting. But, the one positive thing is that it gave us enough time and space to focus on some things that will help my daughter, Maddy develop her independence. Through texting and zooming she can communicate in the same way that most of the rest of the world communicates.

Dorothy Blakeslee, family advocate

Our silver lining is spending more time with our son Stephen, who has autism. His compassion and love are calming forces during this difficult time.

Andrea & George Graham, family advocates

The joy of my life, Gabriel, is 11 years old, and autistic. He has been non-verbal since birth. During the Pandemic, with the one-to-one focus on him, he began to truly find his voice with words... phrases, and now, we are working on sentences.

Elisha DeMaria, family advocate

Our 49-year-old son, Bobby lives at home with us. Although he misses his day program of 28 years, we have enjoyed not getting up at 6 a.m. to get him ready for a 7:30 a.m. bus pickup. We will enjoy it even more when we move the clocks back to dark winter mornings.

Carol and Tom Hopkins, family advocates

I bought tons of birdseed and I watch the birds and squirrels come and eat it every day. It's amazing how many different types of birds show up for food.

Scott Feldman

Not being able to discuss stroke education with the public, because of this virus has been devastating. It has been my dream since 2003. So now, whenever I have free time available the sound of music or the rustling of pages of a book I'm reading rescues me from the reality I and so many others are facing,

Bill Dailey

The quarantine has given us a lot to be thankful for! Thank you for friends, for technology, for helping us continue to learn and adapt, and for making us all more vigilant about hand washing and about our health. We are stronger because of it!

Jenni Clark

During the pandemic, I've enjoyed spending more time with my father, mother, and brother, Jeffrey.

*Jonne Leonor
NJCDD Communication Intern*

In the beginning of this global pandemic I was very depressed. After realizing the pandemic was getting worse and we would be confined to our homes and working from home for longer than anticipated, I had to find ways to pull myself out of my depression. In retrospect there have been several silver linings for me in this pandemic. Here's one of them.

My son loves chicken and broccoli from a Chinese restaurant. Before the pandemic, he ate it at least once a week. During the lockdown we stopped ordering takeout because we wanted to limit our interaction with people outside the family. However, my son, being autistic and set in his ways, constantly asked me to order it for him. Finally, I decided I had to learn how to make it just like take out. After several missteps I finally succeeded. The silver lining is that I've mastered cooking authentic Chinese chicken and broccoli and other Chinese dishes. I am proud to say I can make this dish just as good if not better than the Chinese restaurants in my area.

I also have had a lot of time to work on projects around the house and complete some of the many things I had on my to do list. I cleaned and rearrange the kitchen cabinets and pantries. I also cleaned all of my closets; and donated lots of clothes and other home goods to our local homeless shelters. The one project I'm most proud of is converting my extra bedroom into a fully-functioning guest room.

The bottom line and the real silver lining is that by keeping busy by working on all of those projects I did not have the time or the energy to be depressed. I learned to be grateful. I'm grateful that my family is doing well; grateful for the time I spent with my family and the time I had to learn and do new things. The pandemic is not over but I have learned to look on the bright side, to be appreciative, to find joy in everything I do and to keep moving forward each day because this too shall pass.

Jennifer Owens, family advocate

P&F



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

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

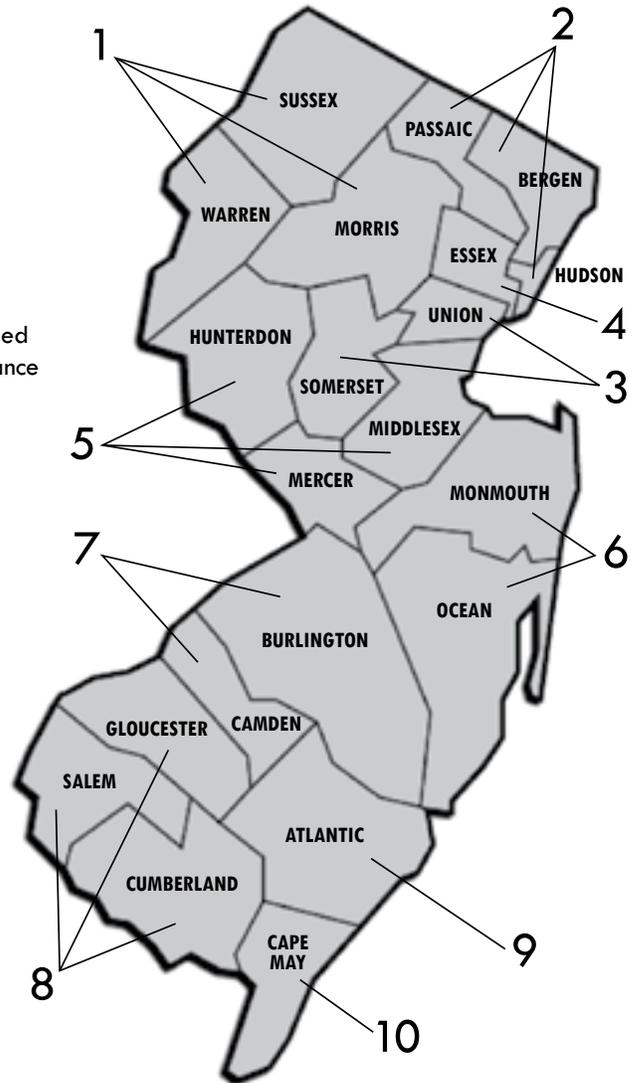
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

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

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

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



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

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

THE FAMILY SUPPORT ACT OF 1993

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

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

1 SUSSEX, WARREN, MORRIS

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

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

7:00 p.m.—8:30 p.m.

2 BERGEN, HUDSON, PASSAIC

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

Meets the third Monday of each month
Secaucus Public Library
1379 Paterson Plank Rd.
Secaucus, NJ 07094

6:30 p.m.—8:30 p.m.

3 SOMERSET, UNION

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

Meets the third Tuesday of each month
Arc of Somerset County
141 S. Main St.
Manville, NJ 08835

7:00 p.m.—9:00 p.m.

4 ESSEX

RFSPC#4
e-mail: rfspc4@yahoo.com
Chair: Yolanda Smith

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

7:30 p.m.—8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

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

Meets Second Saturday of each month
South Brunswick Library, 110 Kingston Ln.
Monmouth Junction, NJ 08852

10:00 a.m.—12:00 noon

6 MONMOUTH, OCEAN

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

Meets the second Thursday of each month

The Arc of Ocean
815 Cedar Bridge Ave.
Lakewood, NJ 08701

6:00 p.m.—7:30 p.m.

7 BURLINGTON, CAMDEN

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

Meets the second Thursday of the month

Wegmans (Cherry Hill, NJ) 2nd floor cafe
2100 RT-70 W
Cherry Hill, NJ 08002

Even months: 7:00 p.m. - 8:30 p.m.

Odd months: 12:00 p.m. - 1:30 p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
e-mail: RFSPC8@gmail.com
Co-Chairs: Amy Kiger, Elena Gardner

Meets second Thursday of each month

9 ATLANTIC

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

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

Meeting times and dates TBD

10 CAPE MAY

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

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.

**DURING THE PUBLIC HEALTH EMERGENCY,
ALL MEETINGS ARE HELD VIRTUALLY.**

If you are interested in attending, please
contact a chair to request a meeting link.

A Tribute: The People & Families Production Team

Editor's Note

During the evolution of *People & Families* magazine many dedicated professionals have remained behind the scenes—until now—writing, photographing, designing and printing a very professional and meaningful publication.

This story highlights the valuable work of an incredible team of seasoned professionals who help shed light on the lives of people with disabilities and their families.

A Short History of People & Families Magazine

Any discussion of the history of this magazine has to begin with the late Ethan Ellis, former director of the New Jersey Council on Developmental Disabilities.

The magazine was part of an extraordinary period in the history of services for people with disabilities.

Not only did the magazine report on developments, it played an integral role in shaping history and public policy by telling stories that mattered, to audiences ready to take action. It helped to galvanize a movement.

The magazine began as *People with Disabilities* in the early 1990s, in the aftermath of the infamous Willowbrook expose and echoed calls for broader changes in the ways in which supports were provided to people with disabilities. At that time, there was a swell

of federal legislation around working opportunities and conditions, civil rights, special education, and accessibility.

Ethan Ellis was a part of those fertile civil rights efforts. He knew that for the vast systems of services for people with developmental disabilities to change—with its institutions, large powerful labor unions, sophisticated parent advocates, and centralized bureaucracy—more needed to be done. There was still scant focus on the people with I/DD who should have been the central focus of those efforts.

The launch of *People Magazine* was part of a strategic campaign to help shift New Jersey from a state that relied on developmental centers, to one that promoted independence and flexible community supports.

Despite the progressive language included in the federal legislation creating the Councils on Developmental Disabilities (Formerly DD Councils), the New Jersey Council was a governmental arm of that vast system and, as such, driven by that system's priorities. Ellis worked behind the scenes with the new director of the state's Division of Developmental Disabilities, to talk about steps

needed to meaningful change. They sought a seismic shift in who controlled that system—a shift from program-based models to people-based supports... and a dramatic reduction in the number of people living in institutions.

New Jersey closed its first developmental center, Johnstone Training Center, and soon behind that, the North Princeton Developmental Center. By most measures, those closures were successful: residents were happier in their new homes in the community; families, even most of those that opposed the closing initially, agreed that the changes were



Ethan Ellis, former director of the New Jersey Council on Developmental Disabilities

positive. Politicians came around to offer support and some even helped lead the way.

But those battles were not easy. In nasty and misleading public “awareness” campaigns against the closures, people with significant disabilities were portrayed as helpless victims, unable to make choices, and in danger of serious harm if they left an institution.

Ellis knew that such messages would set the advocacy work back, and would disempower people with developmental disabilities. Under his direction the Council launched *People with Disabilities* magazine. It focused on the humanity and diversity of the people at developmental centers, and personalized the highly political process of closure, which had focused on systems and money and models and, ultimately, control. From the macro of billions of dollars in funding to the even more important micro of individual lives, *People with Disabilities* was there to remind the players in the entire DD service of the people who should come first.

After the successful closures of Johnstone and North Princeton, the magazine continued to detail the un-spun issues important to the lives of the people with disabilities themselves. The magazine helped to ensure that the main protagonists of their own lives were the people with disabilities themselves.

A few years later, as the family support movement gained strength in New Jersey, the Council launched a sister publication, *Families Magazine*, which chronicled the lives and experiences of caregivers, siblings, and parents. It too had a political purpose: to build and propel public support for family support services.

Eventually, the two magazines were merged into one, becoming *People and Families* magazine. It remains a voice for people with disabilities and their families, but it has shifted from a politically hard-hitting, ‘in-your-face’ read, to one that

focuses on education and information sharing, while still personalizing the issues of the day.

The three-decade run of the publication—from its original format as *People* to the now familiar *People and Families* of today—is an extraordinary chronicle of extraordinary times and extraordinary lives. It is worth going back and revisiting. You might be outraged, befuddled, shocked, tickled, provoked, delighted, informed, and enlightened. But you won’t be disappointed.

Maryann Hunsberger writes because she knows it makes a difference.



Maryann Hunsberger has been writing for the NJCDD since 1996.

Since 1996, she has been involved with the New Jersey Council on Developmental Disabilities, first as the writer for the Monday Morning Project newsletter, and later, for *People with Disabilities* magazine and *Families* magazine, publications that were eventually merged to make *People & Families* magazine. When Ethan Ellis hired Maryann, she was a resource parent for the Statewide Parent Advocacy Network (SPAN) and facilitated a monthly tri-county training group for parents of students with disabilities.

Maryann lives in Camden County and knows personally the challenges faced by those about whom she writes. She is the mother of two adult children, both of whom have disabilities, and describes herself as “a wheelchair user.”

Before writing for the Council, she was managing editor of a nonprofit magazine for ten years, and before that, she worked for the federal government for ten years.

“I like doing work for nonprofits and state agencies because I like doing meaningful work that helps people and that is what writing for *People and Families* does; it helps the disabilities field make progress and it is a chance to tell people’s stories.”

Brenda Considine got into the field of developmental disabilities in 1984, working for Autism NJ, then known as COSAC. She later moved on to The Arc of New Jersey to direct their public policy office. In 1991, she was invited by Ethan Ellis, former director of the Council, to write opinion pieces on special education for what was then *Families* magazine. At that time, she was working on public policy and advocacy efforts around the closure on Johnstone Developmental Center and advancing inclusive education.

“It wasn’t until my son was diagnosed with an autism spectrum disorder in 2000 that I really understood the field,” she said. “That is when the work, and its importance, hit me in a new way.”

A resident of Mercer county, Brenda loves writing for the magazine because it’s a chance to tell stories about how policies and programs affect real people. “It helps decision-makers see how policies and practices impact the lives of people with disabilities and their families.”

Jonathan Jaffe

Jonathan Jaffe has written for *People & Families* magazine (P&F) since 2003. As the owner of Jaffe Communications in Cranford, P&F was his firm’s



Brenda Considine writes for People & Families magazine

first client. Jonathan, has a graduate degree in journalism from NYU. He taught journalism as an adjunct at Rutgers University, had been a newspaper reporter at the Star Ledger for ten years prior.

One of Jonathan’s first assignments as a journalist was in 1990 when the ADA was passed. He wrote many stories for the *Star Ledger* about accessibility and whether New Jersey municipalities in NJ were complying with the new law. His involvement became more personal in 2011 when he and his wife had a baby boy who is on the autism spectrum.

His interest in recent years has focused on autism and how it relates to providing all students with a thorough and efficient education. Working for P&F gives him great satisfaction because he has the ability to focus on very relevant issues not usually covered in other media.

Rebecca Shavulsky

Rebecca Shavulsky was in the midst of an eight-year photography project, chronicling the life of a Brooklyn girl with spinal bifida. She was using her camera to share the story of a Latino family trying to get the services they needed through an unsympathetic health care system.

Impressed with her work, a photography client told Rebecca about an opportunity to do steady work within the disability community and connected her to the former NJCDD Executive Director, the late Ethan Ellis. It was the mid-1990s, and Rebecca found herself in Trenton, in Ellis’s office, reviewing her portfolio and discussing her future with *People & Families Magazine*.

“We hit it off; Ethan was amazing,” Rebecca recalled. “He brought me in to the magazine and was so encouraging. Ethan was such a champion of my work; a real father figure to me in so many ways.”



Jonathan Jaffe writes for People & Families magazine

Rebecca, who lives in New York, started in freelance photography in Baltimore, working for the *Baltimore Sun* and other publications. She attended the International Center of Photography School in New York, and had work published in *The New York Times*, the *Village Voice* and other well-known periodicals.

But there is no doubt where she has the most pride: serving as the main photographer for *People & Families* magazine over the past quarter century. Rebecca has used her lens to tell countless personal stories and to promote the many issues and concerns facing people with developmental disabilities, and their families, in New Jersey.

“I feel so much hope for people with disabilities and their families,” she said. “They are such strong and resilient people. I always find inspiration in their lives and in their stories. I really, really enjoy photographing them. Over the past 25 years, I have continued to draw so much inspiration from them.

“Working for this magazine has made me a better person. I am eternally grateful for the opportunity.”

CranCentral Graphics, LLC

A magazine can only look as professional as its design. And that is why the NJCDD relies so heavily on the dream team of Max and Anita Crandall, who run CranCentral Graphics, LLC, an approved vendor for the State of New Jersey. Their background is in textbook and magazine publishing, as well as advertising.

The couple has been designing *People & Families* magazine from their office in Lambertville for 13 years. In 2007, Norman Reim, former editor of *P&F*, reached out to Anita and Max to see if they were interested in doing the paging, layout and design of the magazine. The work has proven to be a



Rebecca Shavulsky's work has been published in The New York Times, the Village Voice and other well-known periodicals.

cornerstone of their business.

“We’ve seen the content evolve over the years with articles about the importance of advocacy, as well as stories about many personal, and professional success stories within the disability community. These stories are inspirational, and clearly provide hope for solutions to issues that people with disabilities, and their families face daily,” Anita said.

Each issue has its very own design. Anita and Max read all the articles, review all the photos, and then launch a design process that gives each issue of

the magazine a personal look, directly relevant to the content of the articles and images.

Max noted the quality of journalism in the magazine has always been excellent, which helps the couple best design each issue. “It is a real privilege to be part of this magazine and part of this team,” he said.

Anita added: “We are fortunate that everyone we work with is a consummate professional. The quality of the work we receive is so impressive. And that’s why it is so enjoyable to create a special look for each story that encourages people to keep turning the pages.”



Max and Anita Crandall

AJ Images

Janet Greeble is the “J” in AJ Images. She is president and founder of the woman-owned printing firm she started with her husband Arnold in 1966.

For the last 25 years, AJ Images has been printing *People and Families* magazine for the New Jersey Council on Developmental Disabilities. The industry has changed dramatically during that time. Today, they use a state-of-the-art 8-color environmentally-safe printing process. As an approved vendor not only for the State of New Jersey, but also for the federal government, AJ Images has a number of other government contacts to print everything from

business cards and stationary, to booklets, flyers, magazines, signs and banners.

Janet and her family have a personal connection to disability. She recalled one edition of the magazine that particularly helped her family better understand the needs of one of her grandchildren who was diagnosed with bipolar disorder. She has a longtime friendship with the founder of ASPEN-NJ, a statewide organization that works to support those affected by Asperger syndrome. AJ images produces ad journals for that nonprofit agencies fundraising efforts at no cost.

Greeble described her employees as extended family, many of whom have been with the company for years. **P&F**

The AJ Images staff. Janet Greeble is at center in white blouse, next to her husband Arnold, at her left.





People & Families magazine in production at AJ Images.



Helper Patty placing the finished magazine in boxes for shipping