Adjusting to the New Normal
Living with COVID-19
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7 ADJUSTING TO A NEW NORMAL

Living with Covid-19

People with disabilities and their families have been dealing with huge challenges and changes in routine that have arisen from social distancing and isolation, schools, and lockdowns. Every facet of life: home, school, work, transportation, even going to a doctor or connecting with friends, has been disrupted by Covid-19.

10 THE UNSUNG HEROES OF CONGREGATE CARE SETTINGS

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Front Cover
Anfal Muhammad-Jenkins and Saafir Jenkins with their son, Saafir Jr.
Photo courtesy of the Jenkins family
When the COVID-19 pandemic hit in mid-March, the impact was immediate among people with disabilities and their families. In response, disability advocates came together to identify problems and to work collaboratively on immediate solutions to the most pressing matters.

The pandemic has prompted many parents to both start, and revise, plans for the financial well-being of their sons or daughters with I/DD.
The COVID-19 pandemic has clearly impacted people from all walks of life. This deadly virus has particularly impacted people with developmental and intellectual disabilities (I/DD).

According to findings published in the Disability and Health Journal, people with I/DD are significantly more likely to become seriously ill or die if they contract COVID-19. Researchers found the fatality rate for people aged 18-74 was 4.5 percent for people with I/DD compared to 2.7 percent for others.

While it is not clear why people with I/DD experience higher risks of death from the virus, the findings indicate this group had more pre-existing conditions including hypertension, heart disease, respiratory disease and diabetes. The researchers also noted that living in congregate settings where it’s harder to limit the spread of COVID-19 may also be a factor.

As of early July, all five of New Jersey’s developmental centers had outbreaks. Of those, 450 residents had been infected and 33 died. New Lisbon had the highest amount of infections and deaths of all DCs, with 194 residents infected, 133 staff infected, 10 resident deaths and one staff death.

Individuals living in licensed settings and their own homes have experienced COVID-19 to a lesser degree than those living in larger congregate settings (36 percent of individuals positive in developmental centers vs. less than 1 percent positive in state licensed community settings).

In spite of these disheartening statistics, individuals, families, advocates, agencies, and government entities continue to band together nationally and locally to help minimize its impact.

New Jersey state leaders and stakeholders have set an example in New Jersey and across the country in collaborative efforts to problem solve ways to minimize greater risk and exposure to COVID-19.

The DD Act Partner Agencies, Disability Rights New Jersey, the Boggs Center on Developmental Disabilities and NJCDD, along with Ombudsman Paul Aronsohn have banded together and engage with individuals and families in regular town hall sessions to listen to what folks are experiencing by advocating and generating resources in response to what we are hearing. We have worked tirelessly to incorporate your voices in current policies like hospital visitation, access to critical care resources, group home visitation and day program reopening.

On July 26, our nation celebrated the 30th anniversary of the landmark Americans with Disabilities Act of 1990 (ADA).

The ADA provides protections against the discrimination of people with disabilities in several areas including employment, education, health care, recreation, transportation, and housing.

Over the last 30 years, we have made real gains both nationally and locally. However, inequalities still exist.

People with disabilities continue to face significant challenges including health disparities.

This special edition of People & Families Magazine highlights the impact of COVID-19 on individuals with I/DD in New Jersey, and how organizations responded to meet new and unanticipated challenges.

This pandemic continues to force us to seek new and creative ways to effectively support individuals and families. In spite of these monumental challenges, we must continue to remain vigilant in our efforts to ensure better and more meaningful lives for the people and families we serve.

Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities
Adjusting to a New “Normal”

Living with Covid-19

By Brenda Considine

Ryan Roy, a 31-year-old advocate from Bergen County, believes the Covid-19 pandemic is a lot like the popular song by the rock band, Queen: “The show must go on.”

Before the virus hit, Ryan volunteered at his county Center for Independence, and worked at St. Philip the Apostle Church answering phones. He also spent time at the local high school as an autism advocate, bringing community outreach to staff and students.

All that came to an end on March 18.

“It has been three months now that I have been home. I was using a lot of services from DVRS and Project HIRE; I was in the hiring process to get a job in Oradell. But when Covid-19 hit the front lines, I could not even go. That is when the state of emergency hit,” he said.

Since then, that is when Roy, his wife and 4-year-old son have been taking recommended precautions, including staying at home, since the Governor issued stay-at-home orders. “But”, says Roy, “life goes on.”

Disproportionally Affected

People throughout the world have been dealing with huge challenges and changes in routine that have arisen from social distancing and isolation, closed businesses and schools, and lockdowns. Every facet of life: home, school, work, transportation, even going to a doctor or connecting with friends, has been disrupted by Covid-19.

These day-to-day challenges also affect people with disabilities, often in ways that are disproportionately difficult. People with disabilities and their families also have to worry about access to information regarding the services they may receive, accessing needed medical services, accessing in-home care and supports, and adjusting to new health guidelines such as wearing masks and frequently washing hands. In addition, the rules around social distancing means that
many people living independently can no longer see the friends and families who are part of their natural supports.

**School Closures and Special Education**

For many families and students, remote learning has become a daunting new challenge. Parents have taken on the role of teacher and therapist; often while working remotely. In fact, early in the shutdown, it was not permissible for students to receive related services such as speech, OT and PT through a virtual platform, all but ensuring regression.

Anfal Muhammad-Jenkins always wanted more time to observe how her 6-year-old son Saafir Jr. was learning in school. Remote learning gave her that chance.

Saafir attends a private special education school in Verona which provides live—and intensive—remote learning every day. He has direct instruction each morning, with other classes like gym in addition to his therapies, interspersed throughout the day. Eventually, this busy schedule meant that Muhammad-Jenkins had to take a month off from her job.

“I had to be there to keep him on task, but I also got to observe him with his teachers in real teaching—I got to see firsthand how and what he is learning,” she said.

She described Saafir as a “sensory-seeking child” who needs physical engagement and physical interaction. “He does not enjoy online learning—we have to fight to get him in front of the computer, and it is hard because there are transitions all day.”

Despite the challenges, Muhammad-Jenkins believes Saafir’s private special education school is doing far better than a lot of other schools. “From day one, they were doing live learning with teachers—and as soon as the therapies were allowed, they were doing that too,” she said.

Muhammed-Jenkins looks for the silver lining. She appreciates the opportunity to focus on Saafir and directly witness his classroom learning.

“This has caused us to slow down. We were rushing all over. Now, I can focus on home. Moms are the champions right now,” she joked.

She is delighted by the higher degree of accessibility, too.

“Now, we don’t need to get a babysitter and have to be gone for hours just to go to a parent meeting. The changes from Covid-19 have been re-orienting in a good way... I love not having to commute—now I get to save hours that I gave away.”

“There are so many emotions you go through during this. As parents of children with autism, we were already isolated,” she said. “We were kind of prepared, but on the other hand, we have no resources when we need help.”

**Family and Individual Supports**

Sara Olexsak, a support coordinator with the Progressive Center for Independent Living (PCIL), finds that the people who need the most assistance were family members who are used to handling all of their children’s needs on their own. Like parents who are now facilitating online learning, parents of adults are also facing unique challenges.

“When Covid-19 first happened, I reached out to all of my clients to see what their plans were and to help in any way possible. I was surprised to find that the people I usually don’t have to check in on—parents who have their kids at home and usually take care of everything—were the ones who needed the most support as they were afraid of leaving the home and putting their child at risk,” she said.

**Fears of Infection and Increased Health Risks**

The Covid-19 crisis has completely changed the landscape in which services are provided to people with I/DD. Due to fear of infection, people have had to make difficult decisions like sacrificing certain in-person services to decrease risk of contracting coronavirus. Circumstances are particularly challenging for adults living in group homes and other congregate settings.

Due to scarcity of personal protective equipment (PPE) especially at the beginning of the pandemic, it was difficult for group homes to provide staff and residents with necessary gear such as masks and gloves. While the state released specific guidelines related to congregate settings
such as nursing homes and developmental centers, guidance for group homes came later and in less detail. Gaining access to tests was difficult at the beginning of the pandemic, even as the virus spread in some group homes.

“The biggest difference between group homes and other settings that I noticed was access to testing,” said Olexsak. “This had a big impact on group homes, as many asymptomatic people could not get tested, even if a staff member or housemate was exposed to Covid-19.”

Without knowing which residents and staff are infected, it is challenging to appropriately place staff in homes in a way that would prevent spreading of the virus.

According to the New Jersey Department of Health, 371 people with neurologic, neurodevelopmental, or intellectual disabilities have passed away from Covid-19. Another study by the Autistic Self Advocacy Network (ASAN) reports 30,131 cases of coronavirus among people with disabilities in congregate settings (developmental centers, long-term care facilities, and group homes). Since people with disabilities living in these settings are often more likely to have one or more underlying conditions that compromises the immune system, it is essential that providers have ready access to testing to protect vulnerable consumers and staff while preventing further spread of the virus.

**A New Routine**

Aside from issues of PPE and testing, day-to-day life for many people living independently or in congregate programs has changed enormously. Before the pandemic, a typical routine included participation in a day program or employment, spending time in the community with friends and family, and going on outings with favorite staff members. Since Covid-19, these activities have either been heavily restricted or completely halted.

Individuals must now remain at home where they often are required to wear masks or stay within their bedrooms to allow for social distancing. Lack of contact with housemates, friends, and family is particularly concerning in these settings; according to the American Psychological Association, people with disabilities experience heightened feelings of social isolation. The pandemic only exacerbates this problem. While the current social distancing standards are in the name of health and well-being, this is often hard for people with disabilities to understand.

“People with disabilities not being able to see their families has been really hard,” said Olexsak. “There is now guidance for families who want to visit their families, so it will be important that the state and providers clearly communicate that information so people can visit with loved ones safely.”

While people have not been able to engage with their communities as usual, access to the internet and technology has been somewhat of a saving grace. As some programming and medical services have moved online, gaining internet access has allowed many people with disabilities to stay engaged with the people and activities they care about.

“Some people with disabilities do not use the internet often, but now that services have become virtual, if someone does not have access to technology, they may be stuck sitting at home without much engagement,” according to Olexsak. “Getting internet access really helped a client’s mental health because it allows them to engage virtually.”

**Tired and Stressed**

As a result of the pandemic, Kyle Picone, 24, found his visual art and music classes at Mercer County College were moved online as a result of Covid-19. He is also a member of PCIL where he is now learning how to do activities on Zoom.

“I have never used Zoom before. I prefer to go out and see people. I have been trying to keep myself busy, playing video games, reading comic books and watching movies to keep enjoying myself.”

A Special Olympics athlete, he took part in the summer games this year by competing virtually. “I won a bronze medal in bocce, and it was fine but less fun than before when it was live.”

While it has been great for Picone and others to continue his usual activities virtually, all of the change happening so quickly due to the pandemic is stressful.

“The whole thing is overwhelming and anxious,” says Picone. “I am tired.”
Joe Pearson, 55, has lived at New Lisbon Developmental Center (New Lisbon) for the past 15 years. His sister, Marie Ryan, lives in Berlin, 40 minutes away from the Pemberton Township facility. She has always been pleased with the care her brother has received during his time at New Lisbon.

In early May, however, Pearson contracted COVID-19 from his roommate. He was asymptomatic at the time he was tested. Ryan said that in phone calls with his family members, Pearson has told them he is depressed and terrified of dying from the virus. “He is completely aware of all the illness and deaths at New Lisbon and around the country. He watches TV and understands everything going on.”

It’s difficult for residents such as Pearson to communicate with staff members who are wearing masks. With daily activities suspended due to the pandemic, residents have nothing to do to pass the time. Ryan said that since residents are in quarantine, they can’t even go outdoors or see family members. [Note: The Division of Developmental Disabilities (DDD) began allowing group homes and developmental centers (DCs) to have outdoor visits starting June 21.]

Ryan often has difficulty reaching New Lisbon on the phone. She has no idea what the personal protective equipment situation there is now. Still, she feels that the staff is doing “the very best they can with what they have. The number of employees is limited. Some of them left because they were sick, or afraid of getting sick. The spread was due to the way the place is set up. It was inevitable that people in such close quarters would get the virus. Still, I think they are taking care of my brother as well as they can.”

New Lisbon had the highest amount of infections and deaths of all DCs, with 194 residents infected, 133 staff infected, 10 resident deaths and one staff death. Gwen Orlowski, executive director at Disability Rights New Jersey, said, “I don’t know for sure why there were more fatalities in New Lisbon, but I can speculate where people are more mobile, they interact with a lot of people. This is just speculation. Only research will bear this out.”

The outbreak hasn’t been restricted to New Lisbon. As of early July, all five of New Jersey’s developmental centers have had outbreaks. Of those, 450 residents have been infected and 33 have died. Among staff members, 462 have been infected and one has died.

Orlowski explained, “By the time we sounded the alarm and shut everything down, it was already in the facilities, brought in primarily by the staff, visitors and delivery people. There is a lot of evidence that you can have asymptomatic transmission, especially pre-symptomatic transmission. They were always playing catch up.”

Long-Term Care
Adults of various ages with intellectual and developmental disabilities (I/DD) also reside in our state’s long-term care facilities (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.

According to Laurie Facciarossa Brewer, New Jersey’s long-term care ombudsman, the reasons vary for why these individuals live in LTCs.

She said that sometimes it’s an individual’s choice or a family’s choice. Some people have been in a facility like Matheny (hospital and residential school for people with I/DD) since they were young. “They just grow up there.” Some transition to the community or to a DC, but some don’t. Some have resided in the community in their own home or family home, but an illness or injury resulted in the need for a nursing facility placement.
She explained that some who lived in provider-managed group homes, supervised apartments and even developmental centers have moved to the community, but an illness or injury resulted in an LTC placement for rehabilitation. “They are flipped to LTC because the provider cannot afford the staff to meet their increased needs. The DDD Transition Unit works to find another provider to accept them, but depending on the person’s medical and behavioral needs, it can take a while.”

As with DCs, those living in LTCs are also fearful, depressed and missing their families now. “This isolation is wearing on people. We’ve had residents say they don’t want to live anymore. One resident expressed a desire to kill herself. I told legislators that the isolation solution is taking a toll. They need to offer guidance to allow at least outside visits. I would also support allowing people who are cohorted in the same group: positive, negative, or questionable. Perhaps people in those rooms could congregate in a communal area with appropriate social distancing and masks. The New Jersey Department of Health (DOH) is trying to identify and plan for a restoration of visits, especially outdoors. I hope it comes very soon.” [Note: On 6/19/20 Governor Phil Murphy issued an executive order allowing family members to visit relatives in nursing homes].

Brewer also feels that people with cognitive disabilities need to be allowed to have a designated family member as their support person to assist in their care. “There has already been guidance about that for hospitals. It should also apply to nursing homes.”

As of June 23, the number of the state’s approximately 670 LTCs with outbreaks of COVID-19 is 557. The number of infected residents is 23,832. The number of infected staff is 12,177. The number of people with developmental disabilities in these facilities who have become ill or have died is unknown.

However, the total number of lab-confirmed LTC deaths as of June 23 is 6,248, or roughly half of the total state COVID-19 deaths. LTCs reported higher numbers that have not all been lab confirmed: 6,422 resident deaths and 117 staff member deaths, totaling 6,539 deaths.

As a result of the unprecedented numbers of infections and deaths in our state’s LTC facilities, DOH paid Manatt Health $500,000 in early May to assess the state’s COVID-19 response in LTCs.

The Report
The 100-page report, titled “Recommendations to Strengthen the Resilience of New Jersey’s Nursing Homes in the Wake of COVID-19,” and dated...
June 2, determined that LTCs were understaffed and unprepared to handle such a crisis.

Donna Leusner, director of communications, NJ Department of Health, explained some reasons LTCs were unprepared. “There is a nationwide shortage of PPE for the health care workforce. Early on, CDC testing kits and swabs were also in short supply. In addition, the CDC provided guidance to only test symptomatic individuals, frontline health care workers and individuals exposed to someone who tested positive for COVID-19.”

The report stressed that hospitals were prioritized when supplies and PPE were distributed, leaving LTCs lacking. Laurie Facciarossa Brewer, New Jersey’s long-term care ombudsman, stated, “The North Jersey LTCs close to New York City were hit the hardest at a time when there was still significant confusion about when PPE should be used. The staff was in the community and coming to work. They brought the virus in from the community. Staff members were not wearing masks, in some cases even after it was required in March. We got calls from families concerned that loved ones might not be sent to hospitals if they got sick because hospitals in North Jersey were overtaxed. South Jersey wasn’t hit as hard because there was more known about the virus by the time it reached them. There was more PPE, better compliance with PPE and greater testing by that time.”

Brewer also spoke about the understaffing situation. “In some cases, a lot of the staff tested positive. They’d have to go in quarantine right away. The facility would have a sudden staffing crunch. They’d lose a lot of staff at one time. This caused our phone lines to light up because the residents were suddenly in understaffed facilities.”

“During the worst parts, from the end of March until Easter weekend, the calls from residents were horrifying. They would say they hadn’t had a shower in weeks, hadn’t been changed in 24 hours, hadn’t received their medications or hadn’t been fed. Everything you can imagine that they were dependent on for care hadn’t been delivered. Some facilities imploded later and went downhill in May. We still get calls on low staffing. Our office opened 43 percent more cases From March 1 to June 1.”

Because of this, the Manatt report recommends bolstering the LTC workforce in hopes of avoiding similar devastation in the future. Leusner feels this is the most important recommendation in the report. “We need to strengthen the LTC workforce and that includes evaluating wage and benefit structures, minimum staffing ratios, ongoing education and training and access to health coverage and sick leave. At the same time, the department is considering the report’s recommendations to strengthen its organizational infrastructure to better support all aspects of LTC resiliency.”

Brewer agrees that this recommendation is of utmost urgency. “The state must take steps to improve staffing ratios in long term care. You need to address the need for better pay and benefits for staff. DOH must be given the resources to appropriately oversee LTC. However, increasing the rate of public funding given to LTCs is not sufficient if it doesn’t go directly to the workers.”

**Successes**

Despite the negatives, many positives have occurred. Leusner said, “The certified nursing assistants and licensed practical nurses who work in nursing homes are heroes who went to work every day under the most challenging circumstances. The successes were these health care heroes who provide 90 percent of the direct care in our LTCs. They went to work every day, despite staff shortages and PPE in short supply. In addition, DOH inspected 169 facilities, provided more than 120,000 test kits and distributed more than 27 million pieces of PPE.”

Brewer said, “There were successes every single day. The people who work in LTC have behaved heroically. More than 100 of them have died [Note: 117 as of 6/23/20]. Yet, people are receiving good care every single day. Throughout this, workers were excellent in coming up with ideas so residents could communicate with their families. They would bring in their own tablets and phones so residents could keep in touch with family members regularly through FaceTime and Skype. The staff would even set up these visits for them.”

Jonathan Seifried, assistant commissioner of the Division of Developmental Disabilities (DDD), said the resilience of the residents in the DCs, the dedication of staff and the patience of
families were the bright spots in difficult days. “The residents have endured a difficult period with strength and shown tremendous resilience. We always knew the center staff members were amazing, but they showed such a tireless commitment and deep dedication to residents during this challenging time. The understanding and patience of families, guardians and residents around visitation restrictions [helped tremendously]. We are happy to have recently relaxed these restrictions as the public health environment improves in NJ, but throughout, loved ones have been nothing but understanding and supportive.”

The Future
Brewer believes good things can come out of this devastation. “It’s pretty clear that long overdue changes will come.” The Manatt report recommends requiring each nursing home to hire a senior-level infection control preventionist who reports to the CEO and the board of directors. “Having an infectious disease specialist in each facility is an immediate issue.”

She also feels that each facility needs a designated contact representative. This person’s job would communicate with family members whenever a death or health emergency occurs. “Family members accepted that they couldn’t visit their relatives for the common good. However, there was no disclosure about what was happening in LTCs before April 4, so the families and residents were panicking and calling my office. Around Easter weekend, everything blew up. Residents were getting sick. Staff was getting sick and calling out. Families couldn’t get in touch with anyone at the facility and had no idea if their relatives were even alive. There were so few staff that they didn’t even have time to pick up the phones because they were struggling to provide care. That’s why there is a need to have a designated person to communicate with families.”

Besides having adequate testing and PPE, Brewer agrees with the report’s recommendation that LTCs need volunteer local rapid response teams to provide community support to LTC facilities in crisis. “When these facilities started to implode from a staffing standpoint, there didn’t appear to be anybody waiting in the wings to rush in and help. I’m not pointing fingers at staff at all. Many people were exposed and had to be quarantined. Thousands of staff members were sick. Administrators and directors of LTCs were themselves sick or just came back to work after being sick. It was a dreadful state of affairs.”

According to Brewer, the staff is ready and willing to implement necessary changes because of their connection to the patients. “In a nursing home, the patients live there. The staff members know and care about these patients for years. It’s why they aren’t quitting, why they come back after being so sick, because they care about their patients who are sick or dying. This is why I say they are the unsung heroes.”

She believes, however, that this pandemic has created trauma. “There is trauma among the residents, staff and family members. We will be dealing with the repercussions of that for years to come. One woman couldn’t find her mom who was in transit and she was frantic. I don’t know how these families can handle it. They see their loved ones failing on video and can’t go in and help.”

Brewer feels the state has “learned a lot of lessons. With enough PPE and testing, we can avoid the kind of catastrophe that we’ve had this year. I do think that moving forward LTCs will be safer. Being able to keep people safe is the main thing. We know so much more about this virus now in terms of transmission and asymptomatic positive carriers. As we’ve learned more and as we’ve gotten more PPE, the spread has slowed.”

“The residents have endured a difficult period with strength and shown tremendous resilience. We always knew the center staff members were amazing, but they showed such a tireless commitment and deep dedication to residents during this challenging time. The understanding and patience of families, guardians and residents around visitation restrictions [helped tremendously].

—Jonathan Seifried, assistant commissioner of the Division of Developmental Disabilities

P&F
When the COVID-19 pandemic hit in mid-March, the impact was immediate among people with disabilities and their families.

Questions swirled: How can such a vulnerable population best protect itself from this fast-sweeping, sometimes-fatal virus? How can people with disabilities receive the immediate care they need, as hospitals and care providers are quickly consumed by a tsunami of patients requiring ventilators? And what about the children? How can they receive the same quality education and services they receive in specialized schools when they are forced to stay home?

Disability advocates were quickly swarmed. Their offices closed and their own families facing a societal shutdown, these individuals were thrust forward to address the mounting needs of people with disabilities and their families, many of whom were clamoring for services via Zoom, phone calls and posts on the Internet.

Then, a tremendous thing happened. Disability advocates—who often work in their own silos to serve very similar constituencies—came together to identify problems and to work collaboratively on immediate solutions to the most pressing matters.

Crushed by demand, as Gov. Phil Murphy declared a “state of emergency” and issued executive orders that shut down the state, disability advocates began to work closely in the waning days of March. They shared information and built an informal consortium of support through weekly calls.

That group included the New Jersey Council on Developmental Disabilities (NJCDD), Disability Rights New Jersey (DRNJ), the Boggs Center and Paul Aronsohn, who serves as the state’s ombudsman for the developmental disability community and is a direct link to Murphy’s office.

Their collaborative work boiled down to three specific areas:

- Hospital Visitation Policies;
- Town Hall Forums, to share information among constituents; and
- Emergency Funding.

“Throughout this health crisis, we have been staying in close touch with individuals and families—not just listening to their concerns, ideas and questions, but sharing all of that invaluable input with our colleagues throughout the Administration,” Aronsohn said. “That allowed us to not only help with their specific situations, but very importantly, it allowed us to inform the larger decision-making process in the Governor’s office and in the various departments.”
“I say ‘invaluable’ because no one—absolutely no one—understands the challenges faced by individuals and families better than the individuals and families themselves,” he added. “They are living it. They are experiencing it. And they are therefore in the best position to help us identify what issues need to be addressed and also how best to address them.”

Here’s a breakdown of the collaboration between these various agencies and how their collective work helped ease some of the tremendous, unprecedented burdens on families in crisis.

**Hospital Visitation Policy**

When the pandemic first struck, hospitals went into an immediate lockdown to limit greater exposure to the coronavirus. Patients were not permitted to have visitors, a scary moment for people with developmental disabilities who often have around-the-clock care with specific caregivers and/or family members.

“Immediately, everyone recognized that there would be no visitors at all,” said Jill Hoegel, Managing Advocate, DRNJ. “People quickly jumped on the fact that there was no provision for people with disabilities who need support.”

Hoegel noted that DRNJ was one of the statewide advocacy groups that quickly drafted a letter to Governor Murphy and state officials, voicing the grave concerns of families. Its advocacy is spelled out on a special website that was quickly established: Drnj-covid.org.

Special concern was expressed for those individuals with limited verbal communication skills, difficulties understanding care plans, situational trauma with unfamiliar settings, low stress thresholds and anxiety because of separation from family, friends and care staff.

The concern was widespread. In fact, The American Academy of Developmental Medicine and Dentistry (AADMD) launched a national petition that called for a new hospital visitation policy for individuals with intellectual and developmental disabilities (I/DD). A Change.org petition was also circulated, generating nearly 50,000 signatures.

On the state level, advocates demanded immediate action. The NJCDD and its partners worked with the governor’s office and the state Department of Health, among other agencies, to grant special permission for a support person to stay in the hospital with patients during treatment. A new visitation policy had to be quickly negotiated, thus ensuring people with disabilities would not be traumatized while under lockdown care.

“We heard from so many family members, deeply concerned that their loved ones were in the hospital without them,” recalled NJCDD Executive Director Mercedes Witowsky. “They wondered how the state could have such a blanket policy and then just assume it would not hurt people. So, we put a call out to families to share concerns, asking them to describe how such a policy impacts them. We were flooded with responses.”

Witowsky said that Aronsohn, in his role as state ombudsman, took the message to the governor’s office, along with more than 100 letters from families.

“We found policies from other states that permitted visitors in certain situations,” Witowsky said. “We took the best language from the policies to make suggestions to the state.”

Because of this pressing advocacy, and follow-up discussions, the state amended its hospital visitation policy, allowing up to two people to be identified with one visitor at a time to remain with a patient with a disability, who also has communication challenges, in the while hospitalized.

**Town Hall Forums**

Immediately, communication was critical. People with disabilities, as well as their loved ones and other advocates, were eager to get answers to many valid questions. In response, the NJCDD, the Boggs Center, DRNJ and Ombudsman Aronsohn developed an initial four-part webinar, allowing people in the community to express their concerns, raise important questions and seek answers. Hospital visitation was certainly a top priority, as well as issues pertaining to wearing masks and social distancing.

The webinar recordings can be viewed at: njcdd.org/covid-19-resources/. People were asked to submit questions before each episode at
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 then purchased online and shipped to the families.

“We served as advocates for the grant program, learning how many families were forced to assist children with disabilities at home,” explained Celine Fortin, associate executive director, ARC of New Jersey. “Some didn’t have Internet access, others didn’t have computers or tablets,” she added. “Some couldn’t keep their child actively engaged without a new and different piece of equipment, craft supply or in some cases, a new musical instrument.”

Not only were grants processed and provided, but the ARC of New Jersey also worked with families to explain their rights. Parents were encouraged, for example, to contact their local school districts to provide accommodations for more stable educational opportunities, Fortin said. “We focused on the idea that so many people were socially isolated and we need to do what we could to alleviate that social isolation in this acute health emergency,” Fortin said. “We wanted...
to provide the tools and technology to do things virtually and to keep individuals with disabilities active and engaged.”

Next Steps
As New Jersey continues to reopen, while bracing for the potential of a second, strong wave of the virus, Spitalnik said there continues to be widespread challenges. They come in many forms, such as how to support families who rely on 24-hour, seven-day-a-week care, how to minimize risk and how to respect the rights of people, but to also ensure their health and well-being.

“This pandemic was new for everyone,” he said. “Issues kept evolving and new questions needed to be answered.

“Part of the job now is for government and the advocacy community to take a step back and see what needs to be addressed, as we prepare for the future,” Aronsohn added. “We need to listen about short-term fixes and long-term fixes to better prepare ourselves. Like anything else, we need people with disabilities and their families at the table to be a part of the conversation from the get-go.”

COVID-19 Resources
The Boggs Center
https://rwjms.rutgers.edu/boggcenter/links/COVID-19Resources.html

New Jersey Council on Developmental Disabilities
https://njcdd.org/covid-19-resources/

Disability Rights New Jersey
https://www.drnj-covid.org
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.

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<td>Chair: Yolanda Smith</td>
<td>Chair: Paul Blaustein</td>
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<td>Chair: Anne Borger</td>
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<td>Meets the third Tuesday of each month Wegmans Market Cafe 34 Sylvan Way Hanover, NJ 07054 7:00 p.m.—8:30 p.m.</td>
<td>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.</td>
<td>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.</td>
<td>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.</td>
<td>Meets second Saturday of each month South Brunswick Library, 110 Kingston Ln. Monmouth Junction, NJ 08852 10:00 a.m.—12:00 noon</td>
<td>Meets second Thursday of each month Arc of Atlantic County 6550 Delilah Rd., Suite 101 Egg Harbor Twp., NJ 08234</td>
<td>Meets times and dates TBD Arc of Atlantic County 6550 Delilah Rd., Suite 101 Egg Harbor Twp., NJ 08234</td>
<td>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.</td>
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Contact the Regional Planning Support Council Chair for more information about attending a virtual meeting.
In 1789, Benjamin Franklin said that in this world, nothing can be certain, except death and taxes. Every year like clockwork, most Americans file a tax return, but only about 42 percent of Americans have necessary planning documents, such as a will or trust, to carry out their wishes when they are no longer here. It requires looking ahead and confronting the inevitable. It can feel daunting and uncomfortable.
“Planning for the future is an emotional and sometimes painful process because it can cause a family member to consider their own mortality, and raise fears and insecurities,” said Ellen Nalven, M.Ed., director, PLAN/NJ. While it can be uncomfortable at first, Nalven has found that advanced planning actually brings families peace of mind, and confidence that their loved one will continue to have the life that they have now.

“Knowing that may help them push past the fear and leave clear instructions on how to keep the person happy, safe and secure,” she said.

Paul Blaustein has been planning for the future almost since his son, Jonathan, was born. Blaustein is the chair of the New Jersey Council on Developmental Disabilities, and the father of a 42-year-old man with disabilities. As a young father, he received advice from one of his son’s therapists when he was only a year old.

“While you and your wife are still young enough and active enough, you have to find a place for him to live without you and move him into that home to help with the transition, and you have to be ready to start over.”

He recalls that advice every day, but since the pandemic, it has taken on new meaning. And he is not alone. Nalven said that since Covid-19 hit, her nonprofit agency has seen a significant increase in the number of families of people with disabilities who want to complete life plans, and learn more about the process of life planning.

PLAN/NJ offers special needs trust administration, legal guardianship, home visit monitoring, advocacy, life planning consultation, and representative payee for social security benefits. They recommend a team approach to planning for the financial and personal care of individuals with disabilities.

**Legal Planning**

Paul Prior, Esq., a partner at Hinkle, Prior and Fischer, Attorneys at Law, has also seen the pandemic prompt many parents to both start, and revise, plans for the financial well-being of their sons or daughters with I/DD.

“Many of the calls we are receiving now, and many of the questions we get when we do our webinars, center around guardianship and estate planning,” said Prior. “The Covid-19 crisis reminds us all that life is uncertain. Planning ahead—especially when there are family members with disabilities—is vital.”
Prior knows this firsthand. In addition to his legal and advocacy work, Prior is also the future guardian to his brother with autism. “As a family member, moments like these really bring home the need to have current plans in place,” he said.

Hinkle, Prior and Fischer recommend that families develop a will and comprehensive estate planning process to secure assets and memorialize wishes.

- The Tools for Legal Planning
- A will
- A living will or advanced directive
- Power of attorney
- A trust
- Guardianship or other surrogate decision-making plans, when needed, for an adult child with disabilities

Estate planning does not mean you are rich. Even those with very modest assets have an ‘estate’ which can consist of big, expensive things like a home, but also smaller items that might hold sentimental value. Someone designated to receive any of your property is called a “beneficiary.” The person named in the will to manage your estate is called the executor because he or she executes your stated wishes. Some types of property, including certain insurance policies and retirement accounts, generally aren’t covered by wills. Beneficiaries should be listed when the policies were taken, or the accounts were opened.

A will can also serve to declare who you wish to designate as the guardian for any minor children or adult children with disabilities, once guardianship has been secured legally.

Planning A Life

While it is important to put legal and financial protections in place, and to select the right people to serve as successor guardian, trustee and representative payee, planning for the future requires more.

“Legal documents are important, but knowing who the person is, who their friends and families are, and what they like and don’t like are essential to ensuring a continuity of care,” Nalven said.

She advocates a process called “life planning,” which centers around ensuring a good life for any individual and is especially important for people with disabilities. A life plan communicates wishes, needs, and the desires of the families to ensure a good life for their loved one as well. A comprehensive plan guides future caregivers as to what supports and public benefits the person has or may need in the future, and therefore is instrumental in maintaining those support systems.

Questions for Families to Consider

Where will their loved one live, and with whom?
Who will consider and adhere to their preferences when making future life decisions?
How will they continue to receive and enjoy quality care and life satisfaction at home, school, work, and in their day program?
Will a trustee and/or representative payee be needed to manage their financial responsibilities?
What do we need to put in place to ensure they remain financially comfortable?
Who will make sure that they receive good healthcare?
Who will talk with medical professionals if they cannot?
What else do they need to feel happy and secure?
Who will do for them the many additional things that we do now?
Who will arrange for them to practice their religious faith, observe their birthday, celebrate holidays, arrange for social/recreational activities, and ensure they thrive?
Who will make sure the family’s funeral traditions and wishes are carried out?

(from PLANNJ.org)
Interested in becoming a better advocate for your community? Join your local Family Support Planning Council!

- Learn more about the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) systems and help spread information to other families.
- Organize public forums and provider fairs to help families learn changes and connect to local resources.
- Make recommendations to the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) about the supports and services families need most.
- Become a positive force for change in your community.

Contact

Kyoko Coco | 609-341-3112 | kyoko.coco@njcdd.org
Rebekah Novemsky | 609-984-4510 | rebekah.novemsky@njcdd.org

www.facebook.com/NJFSPC

Supported by the New Jersey Council on Developmental Disabilities
NJCDD.ORG | 20 West State Street, Trenton NJ | 609-292-3745 | njcdd@njcdd.org
“These supports can involve far more than public benefits and services. Future caregivers need to know about the friends and relationships the person has, work and school involvement, how they use technology, and detailed information about the individual’s personal strengths and assets,” noted Nalven.

At times, PLAN/NJ has been appointed legal guardian for a person—with all the right legal actions performed correctly—but no information about who the person is, what they like and are good at, and what priorities the person or their family had for what their long-term living and working life should look like.

“The decisions of a guardian or support personnel should always be guided by the person and the family, so information such as this is crucial,” Nalven said.

Brothers and Sisters
Kara Kushnir is a psychotherapist and licensed clinical social worker (LCSW) who founded one of New Jersey’s only clinical practices offering family systems therapy around adult children with I/DD, with a special emphasis on siblings. She and her twin sister, Kristen, also a psychotherapist, know the landscape well. Their younger sister, Katie has autism.
“When Covid-19 happened, Kristen and I prompted a conversation with our parents. We wanted to know what we would do as a family if someone got sick,” she said.

The process of planning, and answering that question, was very emotional.

“Too often the emotional part of the discussion gets put on the back burner. We talk about the logistics, but we don’t make space for the emotional part. We have to be honest in our conversation—it requires so much vulnerability,” she said.

Kushnir points out the challenging—and opposing—forces that come into play when addressing the emotional part of planning.

“So many parents have had to be strong advocates. It is about being a fighter—a soldier—that is what families learn. When it comes to talking honestly about the future, we have to take our armor off and have these deep conversations. It requires humility and great vulnerability. It is scary, but if we don’t know what comes next, it can be even more unsettling,” she said.

“The greatest gift you can give your family is peace of mind and planning,” she concluded.

Advice for Siblings

1. Start by considering your own feelings, preferences and vision for the future. It may take time to think about the role you want to have in your disabled sibling’s life, reconcile it, and express your own needs.

2. Open the dialogue by initiating a conversation with your parents about the future—to better understand their expectations.

3. Get educated. Even when parents are not ready to have difficult conversations, arm yourself with information and resources, and think about what would work for you when your parents are gone.

4. Make a choice about the role you want, based on what works for you. While parents may have expectations, siblings do have choices and should do things in their own best interest. They do not have to say ‘yes’ to everything. It is better for parents to learn about a sibling’s preferences and plans while they (parents) are still alive so they can shift explications and develop a collaborative plan.

“Siblings need to remember that they did not chose to have a child and are not responsible for their sibling with a disability,” said Kushnir. “Opting to take on a caregiver role of responsibility for an adult sibling with a disability is a choice, not an automatic assumption.”

5. Get support from others who “get them” such as a professional or someone who is a caregiver for a sibling with I/DD. It is important to connect as a way to help you feel more supported and understood.

“Siblings need to know their limitations and acknowledge their own truth, even if it is a heavy truth,” Kushnir concluded.
Three Questions
Blautstein invites parents to ask three questions: Why? What? How?

“The why is clear here,” said Blautstein. “Our children will hopefully live without us for years. The worst thing I can imagine for our children is that they become emergencies when we die. They lose their family, their home, their friends, their activities and they will be moved to wherever there is a bed that night. This is what we need to avoid.”

The what is next. “We need be sure our children have a home and that we have arranged for care and a successor to make decisions, make sure their needs are met and that they have the resources they need,” he said.

Then we get to the how.
Blautstein has used a process called Charting the LifeCourse to help identify a circle of support, and to identify community resources.

“We use a notebook to record what our son likes, what he does not like, what he likes to eat, how to prepare his food, allergies. My other son calls it an ‘owner manual,’” he said.

As chairperson of the NJCDD, Blautstein is on a mission to help make sure that people have the knowledge and support they need in order to carry out this work and plan ahead.

“We have to help people see how important this is and how to get the help they need to accomplish this. Otherwise, parents’ worst nightmares could become their child’s reality.”

Resources
- Planned Lifetime Assistance Network of New Jersey, Inc.: Lifetime Advocacy for People with Disabilities
  www.plannj.org
- Charting the LifeCourse Framework and Toolkit
  https://www.lifecoursetools.com
- The ARC Center for Future Planning
  https://futureplanning.thearc.org/
- The Arc of NJ Guardianship Go Bag
  https://www.thearcfamilyinstitute.org/resources/guardianship-go-bag.html
- Tools to Help Build a Plan
  https://futureplanning.thearc.org/users/sign_up
- Sibs NJ (on social media)
  https://www.facebook.com/sibsnj/
- A Work of Heart
  https://www.aworkofheartcounseling.com/
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
Jonah, one of more than 2300 grant recipients, enjoys some outdoor exercise on his new trampoline.