Advocates: Collaborating to Preserve Rights & Solve Problems

By Jonathan Jaffe

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 locked-down 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 questions@drnj.org.

The Boggs Center was particularly interested in the mask issue, developing informational pieces on how to wear them and why to wear them.

“The question was whether people with developmental disabilities could tolerate wearing masks based on sensory challenges and the understanding of the necessity for them,” explained Deborah M. Spitalnik, Executive Director of The Boggs Center. “People have to be able to tolerate masks, as they can be uncomfortable. And they have to recognize why other people are wearing masks, as it is traditionally associated with people performing medical procedures that can be frightening or painful.”

Sean Kile practices playing his new piano, funded through the emergency grant

People joining in the town hall forums also expressed concern about the quality of virtual learning for their children with disabilities, who did not have the classroom aides, specialists and other in-person experiences to help guide them. State representatives joined in these virtual meetings to provide updates and hear concerns.

Four of the seminars were completed by the end of May. Four more were scheduled through July, titled, “Reopening & Reimagining: A 4-Part Conversation about Services and Supports for Individuals with Intellectual or Developmental Disabilities.”

NJCDD Emergency Funding

In an effort to help get people what they needed during the crisis, the NJCDD authorized $250,000 in emergency spending for grants up to $500. Nearly 700 applications were submitted, of which approximately 600 applications benefitting over 2300 individuals were approved for funding. To help spread the support as quickly as possible, NJCDD enlisted the support of the Arc of New Jersey by amending a current contract. The Arc of NJ processed the applications and grant awards and, in some instances, expedited the purchases.

Funding was given for such items as handheld 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

Annemaria works virtually with her music teacher while playing her HAPI Drum purchased through emergency grant funding

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 is an opportunity to really ensure that we are providing supports that are truly people-centered," Spitalnik said. "We also need to work with people who don't have as much digital access and reach people who need more information in different languages, such as Spanish."

Aronsohn noted all of this advocacy work was done seven days a week via phone and email, with the prime objective of allowing policy makers to hear the concerns of people across New Jersey, from coronavirus testing to wearing PPE to the allocation of critical resources. There was also a question of fairness, ensuring people with disabilities had equal access to ventilators and other life-saving equipment.

"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." P&F

COVID-19 Resources

The Boggs Center

https://rwjms.rutgers.edu/boggscenter/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