

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 2, 2020



ASSISTIVE TECHNOLOGY

Options and Opportunities for Independence



Accessing Developmental Disability Services in New Jersey

A Resource Guide for Individuals and Their Families.



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

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



Supportive Housing Association of NJ • www.shanj.org

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Front Cover

Assistive technology can open new doors and new possibilities.

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Advocates Shaping Public Policy

Bobbie Gallagher, the leading parent voice behind some of the nation's most important autism legislation, jokingly acknowledges that her earliest advocacy work was rooted in distrust. After two of her three children were diagnosed with autism more than 25 years ago, the Brick Township mother launched one of the first epidemiological studies of autism in New Jersey.

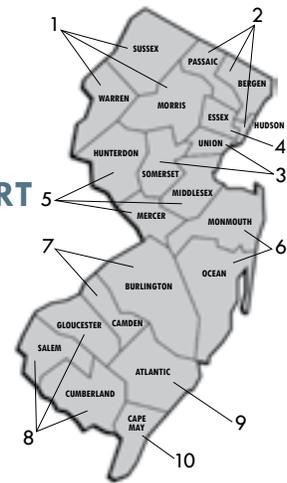


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Advocates Shaping Public Policy

The Arc NJ is celebrating its 70th anniversary. The Arc NJ currently supports 27,000 individuals and families. They are the state's largest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families.

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What Will People with Disabilities Receive?

People with disabilities cannot be denied medical care based on stereotype or a subjective assessment of the quality of a person's life. Treatment decisions must be made on objective medical criteria only.

from the Executive Director ■

Balancing Advocacy with a Global Pandemic

While we were putting the finishing touches on this issue of *People & Families Magazine*, we were at the beginning stages of the COVID-19 pandemic. Sadly, April Dunn, chair, Louisiana DD Council passed away due to complications resulting from this dreadful virus. She was only 33 years young when she passed.



I was fortunate to witness April receive the National Association of Councils on Developmental Disabilities Champions of Equal Opportunity Award last summer in New Orleans. She wore a white dress that matched her bright smile as she proudly accepted her award. April was a well-respected voice that left a void in our community.

We will proceed as planned with this dilemma, as we mark this incredible time of change while accepting that we cannot take anything for granted. We are all vulnerable and may we learn important lessons to help shape our futures as we make our way through these challenging times.

This global health crisis forced us to be much more vigilant and creative in our approach to supporting individuals with I/DD and their families. As a Council, we dedicated ourselves to providing additional valuable information and resources for the I/DD community. We also established emergency funding to support creative ideas to help people remain healthy and stay engaged while practicing social distancing.

Never in my wildest dreams could I have imagined that we would be working so hard to distance ourselves from family, friends, and members of our own communities. This is a very ironic twist that contradicts what so many of us in the disability

community have spent decades advocating for—stronger individual and community connections.

Prior to this global health crisis, the Council convened an Assistive Technology Summit. Participants learned about ways in which assistive technology (AT) can help improve the lives of people with I/DD. We also discussed ways to expand the use of AT in New Jersey.

Current events clearly have made the need for technology much more evident. This issue of *People & Families Magazine* highlights how AT can provide greater opportunities for independence for people with I/DD while maintaining healthy lives in the community.

This issue also highlights advocates who have helped shape public policy, and efforts to better represent people with disabilities in the 2020 Census. It also honors The Arc of New Jersey's many valuable contributions while they celebrate their 70th anniversary.

In closing, I'd like to acknowledge the overnight heroes throughout the State of New Jersey. Thank you for the tireless efforts of our state leaders, health care workers, direct support professionals, countless numbers of individuals, families, agencies and organizations who continue to advocate for better lives for people with intellectual and developmental disabilities. Our direct support professionals in particular deserve special recognition for their heroic efforts.

Mercedes Witowsky

Mercedes Witowsky
Executive Director,

New Jersey Council on Developmental Disabilities



ASSISTIVE TECHNOLOGY

Options and Opportunities for Independence

By Brenda Considine

*"Every once in a while, a **new technology**, an **old problem**, and a **big idea** turn into **an innovation**."*

—Dean Kamen, American engineer, businessman, and inventor of the Segway and iBot battery powered wheelchair

From smart phones to self-driving cars, technology has transformed modern life, opening new doors and new possibilities. For people with intellectual and developmen-

tal disabilities (I/DD), technology holds the promise to expand options for independent living, increase community and workplace inclusion, and reduce costs.

As defined in 1998 by the Federal Assistive Technology Act, “assistive technology” refers to:

Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. AT service is directly assisting an individual with a disability in the selection, acquisition, or use of an assistive technology device.

Enabling Technology is the use of various forms of devices and technology to support a person with disabilities to live as independently as possible. These types of technologies include sensors, mobile applications, remote support systems, and other smart devices. Enabling technology can support a person in navigating their job and community while gaining more control of their environment, and providing remote support and reminders to enable independent living.

Remote Support is an emerging service model that combines technology and direct care to help support people with developmental disabilities living independently. Using two-way communication in real time, such as home-based sensors, cameras, and other technologies, remote support allows off-site caregivers to monitor and respond to the safety and needs of a person with developmental disabilities living in the community.

“We know that assistive technology (AT) can promote greater independence and enable people with I/DD to perform tasks they would otherwise be unable to accomplish or have difficulty accomplishing,” said Mercedes Witowsky, executive director, NJCDD.

Council Action

Access to effective and appropriate AT is a cross-cutting issue, with implications for the NJCDD’s 5-Year Plan in all areas: self-advocacy, family training and information, direct support staffing issues, special education advocacy, employment, transportation, health and wellness, and

Is There a *Right* to Technology?

The 1999 landmark US Supreme Court decision in *Olmsted v. LC* established that the unjustified segregation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA).

The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services.

In spite of this decision, most people with I/DD do not have equal access to the types of technology (e.g., communication devices, mobility devices, smart homes, digital information) that could greatly increase their ability to live and work in the community.

housing. Recognizing its importance, leaders at NJCDD organized a Summit on Assistive Technology last December. They assembled a group of roughly 30 thought leaders—providers and consumers—in New Jersey’s I/DD system. The goal was to learn about ways in which AT can improve the lives of people with I/DD, and to look for ways to expand the use of AT in New Jersey. The day featured presentations by three highly qualified national experts who have used AT approaches to transform their organizations and support people with disabilities. Stakeholders took part in a facilitated discussion concerning the future of AT as a strategy to address issues facing people with disabilities. The discussion began with a review of “why”—the reasons that moving the needle on AT in New Jersey is vital. The conversation centered on helping

people with I/DD live a good life—one that is self-determined.

But technology holds even more promise.

With rising costs of providing services, and the scarcity of direct care professionals, assistive technology offers the opportunity for providers to reallocate resources to serve more people and become more efficient.

“When individuals with I/DD can rely on technology rather than staff people, it allows staff to be reallocated, so they are used more effectively and efficiently,” said Witowsky. “By shifting resources, we can help reduce waiting lists for services, and staff can be assigned to provide other services that are truly needed.”

The Role of Medicaid

While the use of AT to support people with I/DD is not yet widespread, there are islands of

innovation. One of the major factors in the use of AT seems to be funding sources; in states in which AT has been a funding priority, its use has expanded.

Medicaid is the first third-party payer to cover passive remote monitoring for home care. In a 2018 letter to members of Congress, the Center for Medicaid Services (CMS) recognized the need to deliver services in new and innovative ways, based on evolving technologies and the recognition of the growing national shortage of direct service professionals (DSP). They seek to balance innovation and accountability by allowing states to include electronic monitoring devices as “medical assistance” under their state Medicaid plans under section 1915(c) of the Social Security Act.

They may also consider other emerging technologies as long as states provide “adequate

Panel experts; (L-R) Ravi Dahiya, chief program officer, YAI; Nick Filarelli, program director, Core Services of Northeast Tennessee; and Jeff Ballenger, vice president, Supportive Housing and Family Services, Charles Lea Center in South Carolina engaging NJ thought leaders during the NJCDD AT Summit.

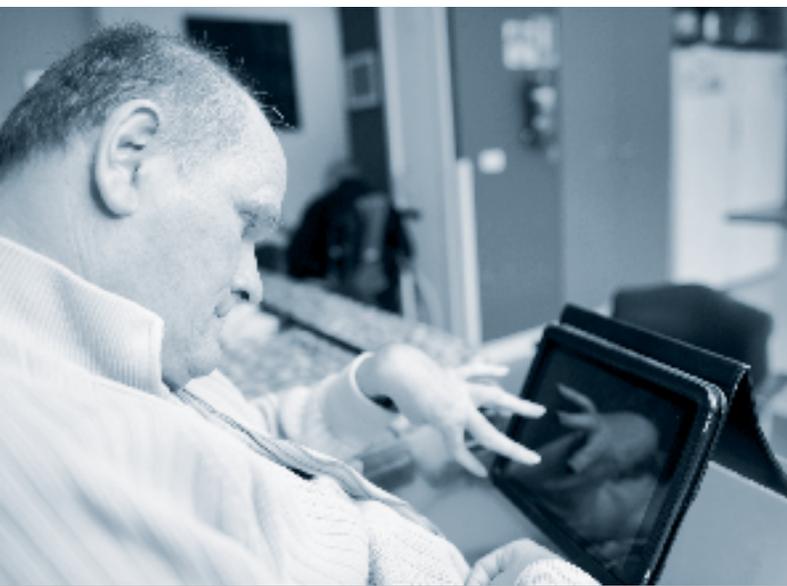


assurances in accordance with statutory requirements, such as they are cost effective, necessary to avoid institutional placement and are provided in such a way that assures protection of the health and welfare of the individual.” They must be designed to promote personal privacy and awareness of rights.

Some states have put into place innovative Medicaid waivers that specifically allow funding for remote supports and other forms of innovative AT. A 2018 report from the University of Washington published by the *Journal of Medical Internet Research* found that two-thirds of the states cover location tracking and activity-monitoring sensors and one-third cover cameras. Only three states have specific service categories that allow them to track when they are paying for any of these technologies, impeding regulation and understanding of their use at the state and federal level.

New Jersey: Ready for Change

The New Jersey system of services and support for individuals with I/DD is well positioned to shift to greater use of AT. In contrast to other states, New Jersey is densely populated and small, making it easier to share resources and information.



In addition, the network of providers is well connected and experienced.

While very diverse, the state’s overall wealth strongly supports access to technology. Cellular coverage and wifi are available in virtually every part of the state. In addition, New Jersey’s Community Care Program and Supports Program within the NJ Comprehensive Medicaid waiver specifically allows assistive technology as a DDD-funded service.

Technology Opening Doors to Independent Living

Advancing Opportunities is one of New Jersey’s leading providers for assistive technology, helping people with disabilities, their families, teachers and employers identify and learn to use the technology that will be most effective in meeting their goals.

Bob(*) is one of the New Jersey citizens who has benefitted from their work. Now in his 40s, Bob wanted to move out of his mother’s house and live on his own. “While he did well at work when there were others to remind him, alone, he had a hard time sticking to a routine. He wanted to live on his own and had the financial capacity, but for safety reasons he was living at home with his mom,” said Vanessa Lombardo, director, Assistive Technology, Advancing Opportunities.

For Bob, the solution was a combination of two products: Ring Doorbell®, a home security system that allows users to remotely monitor movement and see who is at the door, and Alexa, Amazon’s cloud-based voice command system. Ring® allows staff and Bob’s mother to see who was at the door, giving everyone a much deeper sense of security. Alexa® is programmed to do a lot of different things, and is used to help Bob remember to do self-care activities like pack a lunch and take a shower simply by asking Alexa “tell me my morning routine.”

“Bob is living the life he wants to live,” said Lombardo.

(*) The two individuals featured in this story preferred that their names not be used.



Bob's mom was concerned he would put himself at risk by letting someone in. He gave her permission to see who was coming or going through Ring®.

"It is important that everyone has a sense of comfort about it," added Lombardo.

She sees a positive change in the technology options for independence.

"In the last 5 years, there has been a shift. It used to be that people with I/DD needed very specialized technology that had to be purchased through specialty companies. Now, anybody can get this technology off the shelf. When we talked about inclusion, it is a nice connection—everyone knows what it is, and can access it," she concluded

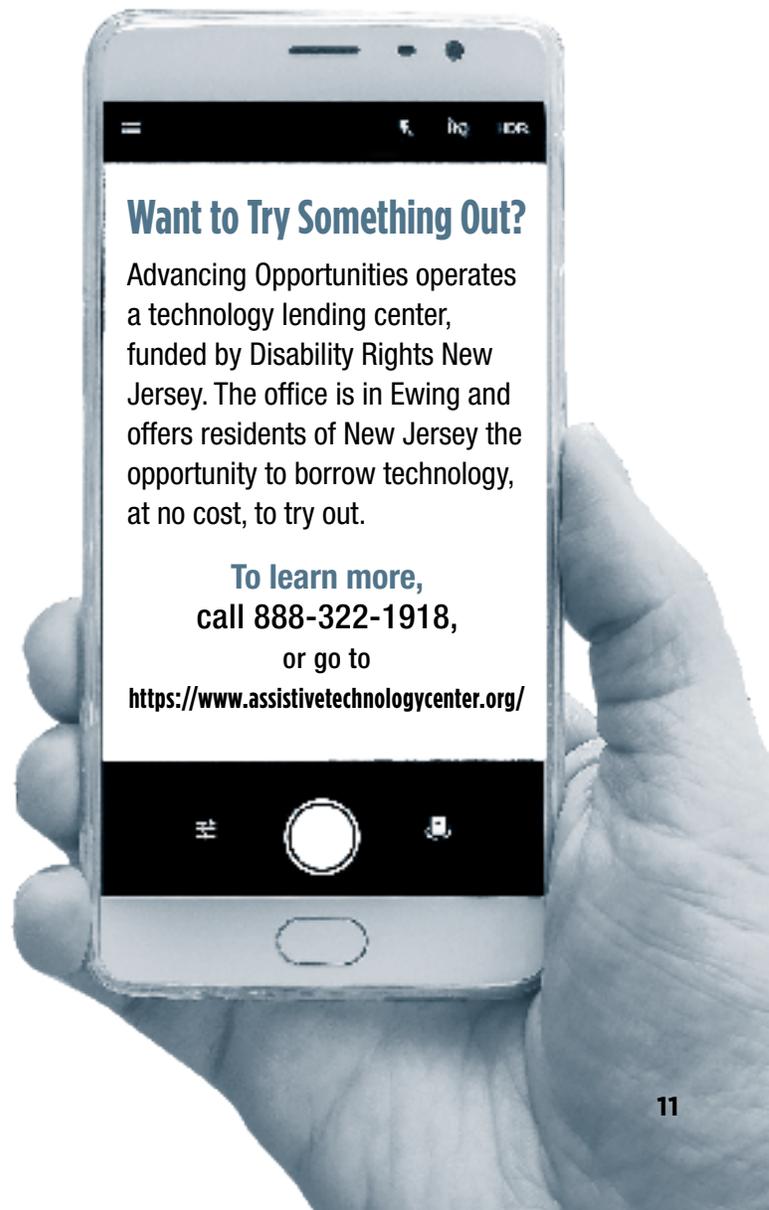
Tom(*) is living in a group home in North Jersey. He has I/DD and some challenging behaviors. He enjoys an active social life in the community, but because he takes medication three times a day, he often had his days interrupted by needing to come back to the group home in order to take medication at specific times of the day.

"Staff was looking at his goals and wanted to work with Tom to help him learn to self-administer his medication. The first question we asked is, 'Is there some technology to help him?'" said Lombardo.

Tom is learning to use MediSafe®, an app on his phone programmed to remind him to take his medication. The app includes a timer, pictures of the medication, refill reminders, and alerts that remind him when to take his medication.

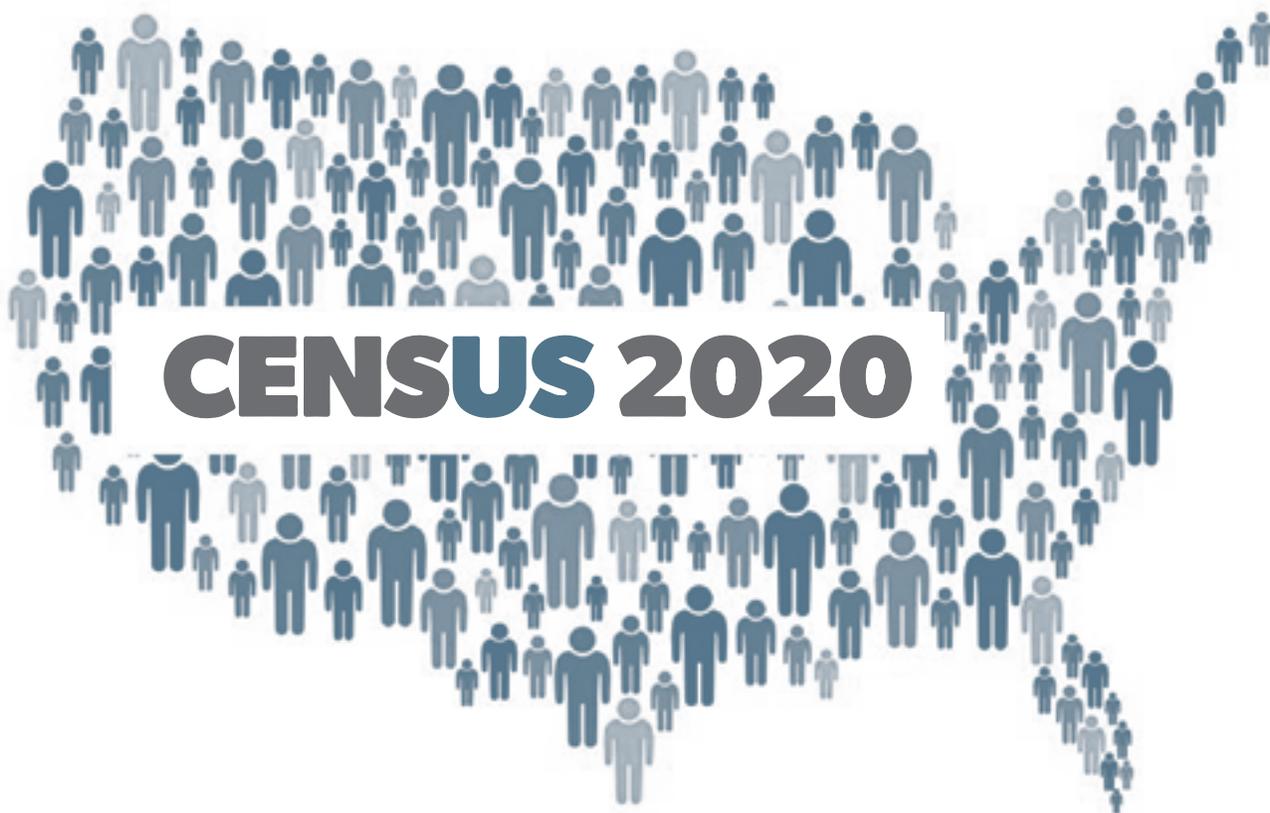
After staff set it up in close consultation with the nursing staff at his group home, they are teaching him how to use it.

"With any AT, it is vital to work with a team to make sure you have all your concerns and outcomes on the table. You need to be very clear on your goals, so you have your bases covered. And it has to be collaborative—you cannot work in a silo," underscored Lombardo. **P&F**



WHY THE CENSUS MATTERS FOR PEOPLE WITH DISABILITIES

By Jonathan Jaffe



On a recent Monday morning, about 15 students, job coaches and workers filed into a workshop at the CEA School in Flemington. The big topic was the upcoming U.S. Census, and how people with disabilities must play a significant role in ensuring the most accurate count of this community.

The hour-long program, through the Arc of New Jersey, explained that Census forms will be arriving via the postal service. People are urged to fill them out and mail, or provide the necessary data online or via a designated phone number. There was also talk about people living in group homes and how roommates can help each other submit this critical information to the government.

Tommy Charles, 20, of Ringoes, a student at the CEA School for people with disabilities, said he had not previously heard of the Census and is now telling others in the disability community to keep an eye out for it.

“There is so much at stake,” Charles said. “We need an accurate count of the population for the Electoral College, and we need an accurate count for people with disabilities to get them the help they need. I never knew how important this could be. We have to let our population know.”

The federal government has estimated that more than a quarter of Americans have some form of disability, yet many advocates are concerned that such a large demographic of individuals are not recognized or have not participated in the decennial census.

According to the National Disability Rights Network (NDRN), New Jersey has 925,580 people with disabilities among our 8.8 million residents. Of that number, there are 216,582 individuals (23.4 percent) in areas of the state defined as “hard to reach census tracts,” defined as areas within the bottom 20 percent of 2010 Census Mail Return Rates, equivalent to return rates of 73 percent or less.

The NDRN has ranked all the states in this category to decipher trouble spots, with New Mexico having the most “hard to reach” population of people with disabilities, while Idaho had the best access in 2010. New Jersey ranked 17th highest in these ratings, indicating there are many access issues that need to be addressed, based upon this report. The national average of “hard to reach” locations is 18.8 percent.

As the count now begins for the 2020 U.S. Census, with people responding through May to what is the largest peacetime mobilization in the United States, New Jersey is demanding precision.



Delia Gordon, David Shapoff, Thomas Klein (seated L to R) attend a census workshop at CEA School in Flemington, NJ

Census population data is used each year to allocate more than \$22.7 billion to New Jersey in federal funding, spanning Medicaid, Pell Grants, the School Breakfast Program, and 52 other essential programs, according to 2016 numbers. Critically, Census data also creates congressional districts for the next 10 years of federal elections.

In the last Census 10 years ago, it was determined that New Jersey had lost population and, therefore, lost one member of the House of Representatives, reducing the state’s delegation to 12. With less representation and a smaller population, New Jersey still sends far more in taxpayer dollars to Washington than it gets back.

There is now a substantial push to ensure every person with intellectual/developmental disabilities in the state is counted. To prepare, in August 2018, the state created the “New Jersey Complete Count Commission” to conduct community outreach around the state, reaching all populations.

“Historically, the mobilization of the Census can unfortunately reflect the inequalities of our society,” said Rep. Albio Sires (D-8th Dist.), in an op-ed. “Low-income, minority, and immigrant households are at risk of being undercounted in the Census and losing out on fair statistical representation. Additionally, households with no

reliable internet access, disabled individuals, or children under five are also at risk.”

For the first time in U.S. history, the Census form will be available digitally—accessible online or through a mobile device—in addition to traditional mail and phone options. There will be no question on the Census about citizenship.

A Statewide Effort

The state’s Complete Count Commission is working to ensure an accurate and complete count of New Jersey’s population with a particular focus on the hard to count populations. A key talking point: Participating in the Census is a matter of civic responsibility. To that end, the state is providing grants to local government to help encourage public education and the most accurate count.

Eric Kipnis, manager of constituent relations for New Jersey’s Department of State, said grants have been awarded to 52 non-profit organizations around the state to help spread the message. Grants, funded through the state budget, range from \$5,000 to \$50,000.

They include a \$35,000 grant to Community Access Unlimited in Elizabeth, a nonprofit that serves people with disabilities and at-risk youth focused in Union County but with a statewide reach.

“There is a heavy focus in New Jersey’s hard to count communities. That includes people with disabilities,” Kipnis said. “We need to make sure they have the access they need to complete the form, that they are aware of the Census and that they need to be counted – especially if they live in independent living situations or group homes.”

Bill Webb, a special projects coordinator for Community Access Unlimited, said the group is hosting informational sessions, urging people with disabilities to attend. At these meetings, volunteers and staff are on hand to help people complete the Census. In addition, the nonprofit will be tapping its mailing list, as well as those of

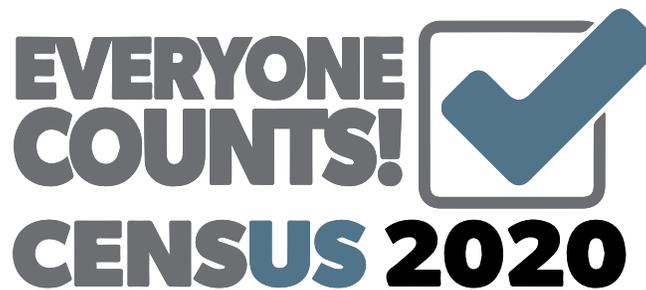
other community providers, to contact as many people as possible with disabilities.

“We are looking for anyone in hard to count populations who might otherwise be overlooked,” Webb said. “The challenge is to find the right people and give them the right messages so they participate.”

Denise Lugo-Fowler, an outreach coordinator with Disability Rights New Jersey (DRNJ), said the organization has been working since December to greatly increase participation in the census, such as creating informational videos and publications representing people with disabilities and the areas that most impact them.

She said the videos and publications will be distributed to the vast network of organizations that serve people with disabilities in New Jersey, as well as state-based media outlets.

Lugo-Fowler noted each video will be closed captioned and available in English and Spanish. DRNJ has also been actively engaging with members of Complete Count Committees throughout the state to share information.



Kipnis said the state is also overseeing Complete Count Committees in 19 counties, which are distributing state funds to help ensure an accurate count. There is a “Census 2020 NJ Coalition,” a statewide outreach and awareness campaign to coordinate all the nonprofit and community-based efforts.

Overall, the state allocated \$9 million for this endeavor, of which more than \$5 million is budgeted for grants. The remainder was allocated for a statewide media strategy and administrative expenses.

Assemblywoman Yvonne Lopez (D-19th Dist.), who serves as a Commissioner on the state’s Complete Count Commission, co-chair of the Middlesex County Complete Count Committee and Vice-Chair of the National Hispanic Caucus of State Legislators Latino Voting and Elections Task Force, said the Census

HOUSEHOLD LIVING SCENARIOS: WHO COUNTS WHERE?

Remember: Your household's 2020 Census response should count everyone who lives at your address all or most of the time.

Multi-generational households

Blanca lives with her partner, adult daughter, and two grandchildren, ages 2 and 4. Her adult daughter pays rent and financially supports her own children.



Who should be counted on Blanca's Census?

Blanca should count her partner, adult daughter and her two grandchildren. Even though Blanca's daughter provides support for her own children and pays rent, she and her children are part of Blanca's household and should be included.

Multi-family dwellings

George and his wife and son live in a house that they rent. Another unrelated family lives in the home—a couple with a newborn baby.



Who should be counted on George's Census?

George should report six total individuals on his Census form—himself, his wife, and his son, as well as the other family residing in his home. Though George may be concerned that he will be penalized for additional residents not disclosed on his lease, Census workers are prohibited from sharing personally identifiable information with other agencies, including municipal code enforcement and landlords.

Children in foster care families

Since the beginning of January 2020, 12-year-old Jessie has resided in multiple foster homes. She has not been at any placement for a prolonged period, but on April 1, 2020, Jessie lives in a foster home located in Middlesex County.



Where should Jessie be counted?

Because Jessie has moved many times and does not have a usual place of residence, she should be counted wherever she lives on April 1, 2020. Jessie's foster parents in Middlesex County should include her on their form.

Living in group homes

Anthony's parents live in Burlington County with his two siblings. Anthony lives in a group home in Mercer County. His parents provide all of his financial support. However, his daily care is managed by the staff at the group home.



Where should Anthony be counted?

Because Anthony's usual place of residence is his group home, Anthony should be counted at the group home. Group homes are part of a special count, known as "group quarters enumeration." The staff at Anthony's group home will be responsible for including him on the Census counts for the facility. Anthony's parents should not include him on their household response; they will only count themselves and Anthony's siblings.

is a pivotal time for New Jersey. The federal government undercounted New Jersey by 33,000 residents in 2010, which included 27,000 children under the age of five years old, she said.

“New Jersey can’t afford an undercount again,” the assemblywoman said. “New Jersey had 15 Congressional districts from 1963 until 1983. Now we have 12. Aside from this, there are billions of dollars at stake and we need to make sure every single person in our great state is counted. That is why I have put all of my efforts into the Census and am urging individuals to fill the 65,000 available Census jobs in New Jersey through the Census Bureau, so that we can ensure an accurate Census that is representative of our growth over the past decade.”

That includes \$21-an-hour enumerators who go door-to-door, \$23-an-hour Census field supervisors, \$23-a-hour recruiting assistants, \$19-a-hour office staff and \$21.50-an-hour office supervisors. These jobs have been advertised at 2020census.gov/jobs.

“The disability community is taking this Census very, very seriously,” said Tom Baffuto, executive director, The Arc of New Jersey. “So often, families are overwhelmed with taking care of a loved one with a disability. The Census forms are not being filled out in many peoples’ homes nor in group homes. People just aren’t taking the time to fill it out.”

In addition to logistical social and structural barriers, people with disabilities face widespread economic inequity, cultural isolation, and discrimination in education, employment and a broad range of societal activities, according to the non-profit Disability Rights Education & Defense Fund (DREDF) in Berkeley, CA.

What’s at Stake

The Census, conducted every decade in years ending in “0” since 1790 and mandated by Article I of the Constitution, is not only for fair political representation. The government relies on the latest Census data to earmark money for education, senior citizen and veteran supports, and other community allocations. The census also deter-



Ashely Ritchey, director, NJ Self-Advocacy Project, The Arc of New Jersey, conducts a census workshop at CEA School in Flemington, NJ

mines financial support for health care, Supplemental Nutrition Assistance Program (SNAP), special education grants and Medicaid.

Medicaid, State Children’s Health Insurance Program (S-CHIP), Head Start and Early Head Start, highway planning and construction, and the nation’s foster care programs are among the top 16 largest federal programs whose funding—totaling nearly \$600 billion a year—depend on Census data, DREDF reports.

Special education grants provide resources to disabled students, tailored to their individual needs. If the U.S. Census Bureau does not conduct a full and accurate count, administrators of special education programs will have no way of knowing how many children they must teach, which school districts need more teachers and where more schools should be built. The Census also shines a light on disparities in housing, health care, employment, and education.



THE 2020 CENSUS IS COMING: WHAT YOU NEED TO KNOW

WHAT IS THE 2020 CENSUS?

The Census is a survey to count every person in the United States, which helps government officials make important decisions that affect our lives. The Constitution requires that every ten years, every person living in the United States must be counted: all ages, races, and ethnic groups including citizens and non-citizens.

Why is participating in the Census important?

Census counts are used to decide where to send more than \$22 billion in federal funding for New Jersey's schools, hospitals, roads – and more. Those numbers impact the next ten years, until the next Census count in 2030. An undercount in 2020 means less funding for ten years for our communities.

Census population counts are also used to decide federal government representation for New Jersey. New Jersey lost a congressional seat and electoral vote after the 2010 Census count, due in part to its Census count.

When does the Census happen? What do I need to do?

Most people will receive letters starting in March 2020 with instructions on how to respond—online, by phone or by mail. Responding to the Census is easy. Most households will be done in ten minutes.

If a household does not respond by late April 2020, a Census Bureau representative, known as an enumerator, will visit to ask the questions in person. This is to help prevent an incorrect count.

What does the Census ask?

The 2020 Census will ask for the name, age, sex, race/ethnicity and relationship to the head of household of each person living in the home, as well as whether they rent or own their home.

The Census will never ask for financial information, social security numbers or credit card/bank information.

Will my information be kept safe?

Yes. Census data with personal information must be kept confidential by federal law.

HOW CAN I LEARN MORE?

To find out more about the Census, visit the
Census 2020 NJ Coalition website at
census2020nj.org.

Now—more than ever—is the time for people with I/DD in New Jersey to be counted, Baffuto said, noting there are constant threats from Washington D.C. that Medicaid funding would be reduced. It prompted The Arc to launch “Census Counts 2020,” an educational campaign to service providers and community members, encouraging them to play a grassroots role in the overall effort.

That campaign includes a substantial social media push, as well as working with local Arc chapters across the state to disseminate materials and to email thousands of people with encouragement to fill out the Census forms. There are also workshops being held statewide for self-advocates, such as the recent event at the CEA School in Flemington, as well as webinars.

“We are doing everything we can in the most efficient way to get the word out that our people need to be counted in the 2020 U.S. Census,” Baffuto said.

The count officially began on January 21 in rural Alaska. New Jersey joined in March, when letters with instructions were scheduled to be sent to 95 percent of households. If people do not respond by the end of April, enumerators will follow-up in person between May-July. The U.S. Census Bureau will release the Census data collected during November.*

Many will be quick to note the Census does not include any questions about disability, showing a gap and a feeling among many in the community that they are a forgotten population, said Erika Hudson, a policy analyst with the National Disability Rights Network.

“Disability is considered a hard to count population,” she said. “It is very important that people with disabilities have a voice and that the Census is accessible to them. The message needs to be that the Census is for everyone, regardless of age, citizenship, color or disability. It is our time to stand up and say, ‘I am here. And I count in the United States.’” **P&F**

The Census Bureau is working to ensure that the Census will be accessible for everyone.

- **Online.** The bureau has assured the public that the online response option will meet the latest web accessibility guidelines, so you should be able to navigate through census materials online without a mouse and use assistive technology such as a screen reader. A video guide in American Sign Language will also be available to help you complete the census online.
- **Phone.** Census Questionnaire Assistance phone lines will be available in English and 12 additional languages if you want to self-respond by phone or have any questions related to the census. You can also complete the census in English via a phone line that uses Telephone Device for the Deaf (TDD/TTY) technology.
- **Mail.** Braille and large print guides will be available to assist you with completing the paper questionnaire. The braille and large-print English language guides, as well as non-English language guides, will be available on the bureau’s website. The Census Bureau will also distribute copies of the accessible guides at partner events, conferences, and meetings.

You can ask someone to help you fill out the 2020 Census. This could be an individual you trust such as a family member or trained caregiver, among others. You can also ask for assistance from Census Bureau staff by calling the Census Questionnaire Assistance phone lines available in English (844-330-2020), Spanish (844-468-2020), and 11 additional languages, as well as an English-language line that uses TDD/TTY (844-467-2020).

* In light of the COVID-19 outbreak, the U.S. Census Bureau adjusted 2020 Census operations and deadlines. Visit www.2020census.gov for more information.



Community Innovation Projects

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

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

SUCCESSFUL COMMUNITY INNOVATION PROJECTS WILL:

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

INTERESTED?

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

1

WHO YOU ARE?

2

WHAT PROBLEM(S) YOU ARE TRYING TO ADDRESS?

3

HOW YOU PLAN TO ADDRESS IT?

4

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



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



MAKING A DIFFERENCE

ADVOCATES SHAPING PUBLIC POLICY

By Brenda Considine

Bobbie Gallagher, the leading parent voice behind some of the nation's most important autism legislation, jokingly acknowledges that her earliest advocacy work was rooted in distrust. After two of her three children were diagnosed with autism more than 25 years ago, the Brick Township mother launched one of the first epidemiological studies of autism in New Jersey.

"It was 1997 and no one had heard of autism. Our family was such an anomaly. We had two kids with autism, and one of them was a girl," she said.

Gallagher wanted to know how many other children with autism were in her community, so she reached out to her local school district, but they declined to help. So, before email, online surveys, and the widespread use of the internet, Gallagher worked with other parents to reach out. In all, she found 45 children with autism in her school district.

"We could not figure out why the district did not want to know how many kids with autism were here. They were so adamant about not helping us. It made us all wonder: *'what else do they*

not want us to know?' Ultimately, it galvanized us," she recalled.

After gathering information in Brick, she took her findings to autism researchers. One of the earliest epidemiological studies of autism, published in 2001 in the journal *Pediatrics*, showed that the prevalence rate in Brick was 6.7 in 1,000—two and a half times greater than the rest of the nation.

That experience launched an advocacy career she never could have imagined. Gallagher would go on to take her message to leaders in Washington DC to build national momentum for more funding and research for autism and related disorders. Working closely with Congressman Christopher Smith (R-4), Gallagher found herself making her case to New Jersey's Congressional delegation as well as leaders at the Centers for Disease Control (CDC) and National Institutes of Health (NIH).

"Never in my life had I even been to Trenton, let alone Washington DC," she recalled. "There were all these high-level people. At the time, I had a high school degree and my husband was a commercial fisherman."



Dr. Bobbie Gallagher, Billy Gallagher, and Austin Gallagher meet with Congressman Chris Smith (R-4)

“We left on cloud 9—thinking something would get done,” she said.

Then they learned there was no funding.

“We asked, is there enough money to do an epidemiological study just to look at the numbers?”

Out of that the ASSURE Act was born, Autism Statistics, Surveillance, Research and Epidemiology Act which passed in late 2000. The bill authorized grants for colleges and universities to report on data; established regional Centers for Autism Excellence; and required the CDC to serve as the coordinating agency and clearing house for data.

She recalls going door to door in the office buildings in Washington, talking to members of Congress.

“There was always someone telling us we were wasting our time. They told us ‘you should be helping them, not counting them.’ People did not understand why counting kids was important. No one understood the scope of the problem—without the numbers, you cannot get funding or research,” she said.

Incremental Change

Through her advocacy work, Gallagher has learned about the incremental nature of public policy and how to work with those who disagree with her.

“We (the disability community) are fighting for every little piece of things; we undermine ourselves. Rather than oppose each other, we should join forces and support each other, then look to improve it next time. Otherwise, we end up with nothing. The idea that legislation or public policy has to be perfect is false; the idea that one bill can do everything is ridiculous,” she stated.

Gallagher, who has since completed a doctoral program and is a behavior analyst, knows the vital importance of research. She urges parents and consumers to take part in research studies.

“Everyone wants change, but no one wants to be part of research that fuels change. My husband Bill and I did it because we had to, and there was no one else willing to do it,” she said.

“When we were in Washington in the 1990s, we were told that there is funding for cancer research because it is ‘sexy,’ but no one knows about autism,” she said.

That has changed.

In 2019, Gallagher was involved in the passage of the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act. The bill expands the provisions of existing legislation and increases the annual budget on autism efforts to \$369.7 million through 2024. New provisions expand activities to include the entire lifespan of people on the autism spectrum.

The office of Congressman Chris Smith credits Gallagher and her husband Bill with prompting the Congressman to “step up his involvement on autism issues”, when they walked into his Ocean County office in 1997 looking for help. Since meeting the Gallaghers, Smith has sponsored four successful bipartisan bills.

“Without a doubt, the Autism Cares Act is because of Bobbie Gallagher,” said Lisa Parles, Esq., an attorney who practices in the area of disability law, and who is also the parent of a young man with developmental disabilities. Parles is another New Jersey advocate who has taken her cause to Washington, DC.

Advocating for Regulatory Change

For the last 5 years, Parles has been engaged in efforts to build more flexibility into state and federal Medicaid policy for those with complex medical needs and severe cognitive and behavioral disabilities.

“I have spent my career fighting for others, but I had never done this before—where I brought my own son’s story to the table,” she said.

Through her efforts, leaders in Washington and Trenton modified funding rules to allow a greater range of options for housing and jobs.

Lessons Learned

- 1) It works:** “I was surprised, but it actually does work,” said Parles. “Talking to policy makers invites them to look at things differently. Medicaid policy is complex, but when you boil it down and put it in plain language, lawmakers ‘got it’ within four minutes,” she concluded.

A History of Family and Consumer Advocacy

Through lobbying and other forms of legislative advocacy, families and self-advocates can provide vital expertise and perspectives to decision-makers leading to improved laws and policies. Nearly every piece of disability-related public policy was born from advocacy—some are even named for the families or self-advocates who helped push the cause.

The “Katie Beckett Waiver” is a Medicaid waiver championed by Katie’s mother, Julie. It allows Medicaid to cover medical services for children in the home, regardless of the parents’ income, in cases where home-based treatment will cost less than or the same as treatment in a hospital.

“Alicia’s Law” is named for Alicia Vitiello. Her New Jersey school district initially declined to allow her to walk in the graduation ceremony because she had additional coursework to complete in her IEP. The law, signed in 2008, allows

students with disabilities the right to participate in graduation ceremonies even if they will be continuing their special education beyond age 18, and will not be accepting a diploma.

In January 2020, Governor Phil Murphy signed “Paul’s Law”, which will authorize parents or guardians to request the use of an Individualized Healthcare Plan (IHP) for school-aged students with epilepsy or seizure disorders. The law is named after Paul St. Pierre, a 13-year-old student from Maple Shade who has epilepsy and advocated for the legislation.

Sometimes, legislative advocacy is born out of tragedy. “Matthew’s Law,” is named for 14-year-old Matthew Goodman who died in 2002 while being restrained in a private institution in New Jersey. The law, championed by Matthew’s mother, Janice Roach, limits the use of restraints and seclusion for people with developmental disabilities.

- 2) **They need you:** “Members of congress are not experts on everything—they rely on information that comes to them. On the issue of housing, individuals with severe disabilities were not being heard so decision-makers were only getting part of the story. They really wanted to hear what was working, and what was not working,” she said.
- 3) **Stories matter:** “One of the groups we worked with was very sophisticated—they had briefing sheets and strategy meetings. The staff would talk for two or three minutes, then let families tell our stories. I thought it would be the experts talking. It is about telling personal stories—you do not need a legal team to write a brief for you. Nothing is more compelling than your own personal stories,” she shared.
- 4) **We have a responsibility:** “There are so many families who cannot do this. The sad thing for us, families of kids with more severe challenges are so swallowed up with day-to-day care, they cannot get out and get involved because they are at home, just trying to survive. Their voices are missing from the discussion,” said Parles.
- 5) **The System is Not Easy:** “You can call or write a letter, but not everyone can afford to take a day off from work to go to DC or Trenton. You need organizations and nonprofits to help,” said Parles. When she realized the voices that had been missing from the discussion, Parles helped to form the National Council for Severe Autism.
- 6) **Opposition will come from places you don’t expect:** Like Gallagher, Parles was surprised by the opposition those she called ‘ideologues.’ “People *talked* about choice, but did not really support choice when they don’t approve of what we were choosing,” she said.



Nina White and Lisa Parles advocating in Washington, DC



Looking Ahead

Parles acknowledges that the war is not over, and that public policy is ever-shifting.

“There is more to be done, but on housing, we moved the needle,” she said. Like Gallagher, she urges advocates to avoid ‘infighting.’

“We don’t have to compete if we respect the right of others to have choices and options—and a full range of them. We need to keep all family and consumer perspectives involved,” she said.

Gallagher is proud of her work, but admits that while her efforts have helped others, they have not helped her.

“My kids did not benefit from my work. It doesn’t really matter how much you do in public policy, you are still a mom when you walk back in the door,” she said.

And there is more: now a grandmother, Bobbie’s three-year-old grandson has been diagnosed with autism. The daycare center that served him kicked him out after only eight days.

“They told my daughter to come and get him—and not come back,” she shared.

This leaves Gallagher frustrated and saddened.

“Why haven’t things changed? This is *my* grandson in the State of New Jersey. What else do I have to do to make the system work?” she asked.

“After 26 years, here is what I have learned; I have learned it is slow. I have learned that we have to stay with it. And, I have learned that we need way more people doing this work.”

Preparing the Next Generation

The act of telling policymakers how to write and change laws is at the very heart of our democracy.

“The Council helps to prepare individuals with disabilities and family members for work as advocates, not only for themselves and their loved ones, but for system change,” said Mercedes Witowsky, executive director, NJCDD.

One of the Council’s flagship efforts is Partners in Policymaking, an 8-month leadership development and advocacy education program for adults with developmental disabilities and family members of young children and transition-age youth. The program is provided through collaboration between the Council, The Boggs Center on Developmental Disabilities, and Disability Rights New Jersey.

The goal is to prepare disability advocates to work toward meaningful change. Participants learn about best practices and important areas for advocacy from nationally-known experts. When they graduate, they have the knowledge and skills to advocate, serve on advisory boards and committees, and work alongside policymakers and state agencies.

Marie Torres Perez is a military mother of a child with complex disabilities and a 2018 graduate of Partners in Policymaking. She now serves on the Council's Subcommittee on Children and Youth where she helps to shape the Council's policy agenda as it relates to special education, family support and healthcare.

Nicholas Taubenslag's goal is to be of service. A self-advocate, Nicholas is interested in transportation and wants to see platforms like Uber and Lyft in the system. A 2019 graduate of Partners, he was invited to take part in the

“After 26 years, here is what I have learned; I have learned it is slow. I have learned that we have to stay with it. And, I have learned that we need way more people doing this work.”

—Dr. Bobbie Gallagher

NJCDD Stakeholder Group on Transportation, which met last spring. There, he helped to shape Council funding priorities as they relate to transportation.

“Engagement by young leaders like Nick and Marie is vital to our work,” added Witowsky, “We need families and individuals to provide their perspective and take charge. They are the hope for the future, and will become the advocates who shape legislation and public policy,” she concluded. **P&F**



The banner features the 'common ground' logo on the left, with 'common' in a sans-serif font and 'ground' in a script font, followed by a stylized 'g' icon. Below the logo is a row of 15 stylized human figures holding hands, including two figures in wheelchairs. On the right, a dark speech bubble contains the text 'Common Ground Online' and 'Increasing Dialog Among Stakeholders in New Jersey's Special Education System'. Below the banner, a dark blue bar contains the text 'The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!'. At the bottom left, there is a list of three bullet points: 'Read about current issues in special education', 'Get updates on legal and legislative developments', and 'Find important resources and information'. At the bottom right, there is a call to action box with the text 'Visit www.NJCommonGround.org to sign-up for a free online subscription!'.

common ground

Common Ground Online
Increasing Dialog Among Stakeholders in
New Jersey's Special Education System

The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!

- Read about current issues in special education
- Get updates on legal and legislative developments
- Find important resources and information

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The Arc®

Celebrating 70 Years of Progress for People with Disabilities

by Maryann B. Hunsberger

Pam Corrigan never dreamed she'd find a second family when she began volunteering for The Arc Gloucester in 1989. Her son, Chris, who has a disability, was 8 years old and attending school. Corrigan was working part time and wanted to volunteer in her spare time. As she gave of her time on different committees for both the local and state Arc (The Arc NJ) throughout the years, she noticed how the volunteers, staff members and board members were always there for each other.

This especially hit home for the Sewell resident when her husband passed away in 2019. "They came from North Jersey down to Gloucester County for the funeral Mass. The local staff and volunteers came and stayed for the luncheon. There were the calls, the cards, and the fruit basket. Several board members and staff even visited my son at his job to make sure he was okay. They did everything someone would do for a family member."

She said this caring atmosphere extends to how they treat their residents. "We just went to the funeral of one of our supervised apartment residents who we knew through bowling. It really is a family."

How fitting, then, that family members were among those honored for their work at The Arc NJ's 70th Anniversary Dinner and Awards evening, held on November 21, 2019. The event celebrated the work of the state's largest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families for the past 70 years.

The Arc NJ currently supports 27,000 individuals and families, including advocacy, self-advocacy and providing information and referral. The Arc of the United States (The Arc US) now has 600 chapters across the country and an estimated 140,000 members nationwide.

The Beginning

Parents have always been the driving force of The Arc NJ's advocacy work. In 1946, Laura Sparks Blossfeld wrote a letter to the editor of the Bergen Evening Record about raising a child with I/DD at home. In her letter, she suggested the formation of a parent organization, which struck a nerve in the hearts of other New Jersey parents.

"She said she couldn't be the only parent out there who wanted her child home with her. The newspaper received so many responses that they sent the mail directly to her. She began having family meetings at her home, but they grew to firehouses and church basements. Even some of the parents whose children lived in institutions came to the meetings," Céline R. Fortin, associate executive director of The Arc NJ explained.

By 1948, The Arc Bergen had formed. The Arc Essex and The Arc Burlington/Camden/Gloucester Counties formed within months. By 1949, they decided to incorporate statewide. The Arc NJ (originally the New Jersey Parents' Group) was born.

The Arc Goes National

In 1950, The Arc US was formed. [Note: Throughout the years, several name changes took place. For clarity's sake, this article will use current names to refer to all disability organizations and laws, regardless of year.]

Public Policy Involvement

In the 1960s, The Arc on the national and state level became involved with advocacy and public policy work, with The Arc US opening a Governmental Affairs Office in Washington, DC. In 1960, Elizabeth Boggs of New Jersey was appointed to the President's Panel on Mental Retardation. Boggs, the parent of a son with I/DD, was an integral member of The Arc NJ Board of Directors and its Governmental Affairs Committee until her death in 1996.

The possibility of employment for people with I/DD became recognized by the government in the 1960s as children grew into adults. The Division of Vocational Rehabilitation Services (DVRS) promised The Arc NJ grants for 2,000 employers to promote on-the-job training for individuals with I/DD.



Christopher Corrigan with his volunteer of the year award in 2017.

Advocacy on the Rise:

Advocacy climbed to the forefront of The Arc on both the national and state levels. They joined legal suits to defend the rights of institutionalized individuals and to ensure the right to public education. Public Law 94-142, now the Individuals with Disabilities Education Act, was enacted in 1975.

An individual's right to live in community-based residential programs was stressed more. Paul Potito came to The Arc NJ in 1976, eventually becoming the executive director in 1990. During his 22-year tenure, Potito said he observed a major shift from an agency that assisted families with children in institutions to an agency that promoted, facilitated and advocated for community development and movement of people with I/DD from facilities.

"The Arc fought for this for years," he said. "We learned in the '70s that there was a certain dignity in taking risks. Things didn't need to be so predictable. Institutional life went on as long as it did because people saw it as a safe environment. But, we learned from the folks we were

...serving that challenges lead to success. It was unheard of before for people with I/DD to make their own decisions about where they wanted to live and work and how they wanted to live their lifestyles. It took a while to facilitate. But, the self-advocacy movement was compelling and made big changes. There was a demand to listen to the people being served. Our work became more focused on the individual—more of a civil rights movement—due to the feeling of empowerment of the self-advocates and the structures they put together, forcing themselves to the table and forcing themselves to be heard. They became very valuable partners in making the whole movement go forward.”

Community Services Expand and Self-Advocacy Becomes Official

The 1980s brought unprecedented expansion of community services to directly support individuals. Self-advocacy went from a concept to a program as The Arc NJ created the New Jersey Self-Advocacy Project. “We learned that people with I/DD make better spokespersons for themselves than advocates do. We felt that with funding and staff, we could better support them,” said Fortin.

Tom Baffuto was hired in 1985 to form and direct Project HIRE, the state’s first supported employment program. Other programs started from 1983 to 1986 were the Criminal Justice Advocacy Program, the Mainstreaming Medical Care Program and the NJ Coalition for Prevention of I/DD.

The Law Is on Our Side— And So Is the Funding

The Americans with Disabilities Act (ADA) became law in 1990, bringing years of advocacy by The Arc on a national and state level to fruition. Fortin began her work with The Arc NJ this same year, when families were still struggling with the waiting list for residential services. The Family Support Act of 1992 and the waiting list campaign, called A Key of Our Own, mobilized families and individuals.

Fortin said, “Everything clicked into place in the ’90s. With the help of the state, we contacted everyone on the waiting list and asked them to



Speaker Craig Coughlin presenting Tom Baffuto with a joint Assembly-Senate Resolution honoring The Arc of NJ on its 70th anniversary.

join our campaign. We received such a response! We heard from thousands of people. The publicity brought out a lot of people who had never applied for services, so for a while, the waiting list numbers went up. These people didn’t even know these services existed, or they had thought it would take too long to bother applying.”

As the state chipped away at the waiting list and additional revenue was put in to support new people, The Arc NJ increasingly supported more people.

Advocating in the New Century

Advances have been made, including the passage of Rosa’s Law, which replaces the outdated term “mental retardation” with intellectual disability in federal health, education, and labor policy. The ABLE Act, which creates tax-advantaged savings accounts for individuals with disabilities, has been created. Attempts by Congress to cap Medicaid have been blocked. But, challenges remain.

The biggest concern facing The Arc NJ is the direct support professional (DSP) crisis. Baffuto, executive director of The Arc NJ since 1998, has

seen his share of predicaments. But, this one is even more crucial than most. He states, “This is the biggest issue the entire field is facing. It’s the thing that keeps me up at night. With the vacancy rates of more than 25 percent and a 44 percent turnover rate, on top of the new minimum wage law and no increase in funding, this has become a crisis. We’ve been very successful in reducing the waiting list, growing housing options, moving people out of institutions. But, if we can’t hire and retain DSPs, we can’t retain the great work we have done.”

The Arc of NJ and a parent formed The Coalition for a DSP Living Wage over three years ago requesting a salary increase for DSPs. “These jobs are not minimum wage jobs. They require skill. When Amazon and Target are paying upward of \$15 an hour, it’s urgent to raise DSP wages. Starbucks just raised the price of a cup of coffee because minimum wage went up, but our DSP salaries didn’t go up. Senator Stephen M. Sweeney, who has been fighting alongside us and is a true champion, introduced a bill in the Senate budget committee to provide a supplemental appropriation of \$16.5 million to go toward DSP

salaries. It always comes down to the funding. The state has to prioritize what is critical.”

Baffuto also spoke about the importance of Medicaid. “You cannot get services from DDD without Medicaid. It’s under constant threat. From our national office on down, we put—and will continue to put—every ounce of energy into protecting Medicaid.”

Through all of the challenges, families remain an important force in achieving even more advancements. Potito said, “We’ve made progress flow because of the involvement of the parents, families and people with disabilities. They need to monitor us and keep us on our toes in finding new, better opportunities in the future.”

Corrigan reflects on the years that have passed since she began volunteering. “When I started, our local budget at The Arc Gloucester was \$1 million. It’s now \$12-14 million. Considering that we started in people’s houses doing bake sales, it’s pretty amazing where we are now.”

NOTE: For more information on The Coalition for a DSP Living Wage or on The Arc NJ’s 70th anniversary, visit www.njdspcoalition.org or www.arcnj.org. **P&F**

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- Keep up-to-date on NJCDD events and announcements
- Stay informed on important developmental disability news from around our state
- Learn more about the NJCDD's programs for self-advocates and families, as well as new ways to participate

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

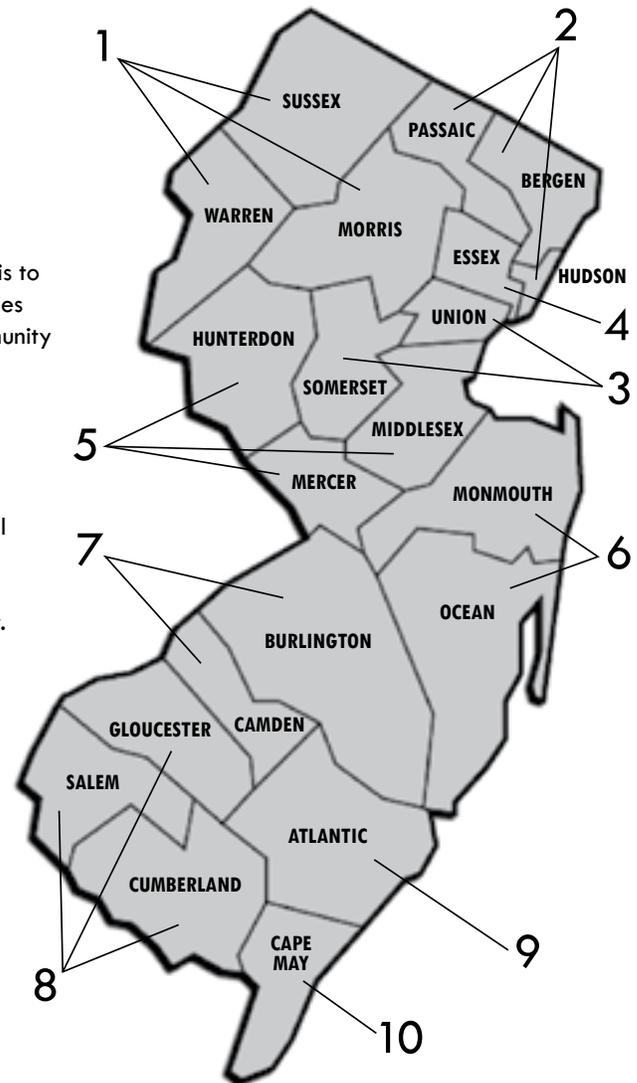
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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' web site at: www.njccd.org,
click on the link for Family Support, and the number corresponding to the
Regional Family Support Planning Council in your area.

1 SUSSEX, WARREN, MORRIS

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

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

2 BERGEN, HUDSON, PASSAIC

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

Meets the third Monday of the month
Secaucus Public Library
1379 Paterson Plank Rd.
Secaucus, NJ 07094
6:30 p.m.—8:30 p.m.

3 SOMERSET, UNION

RFSPC#3
e-mail: rfspc3@gmail.com
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
7:00 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
Wegman's 2nd Floor Cafe
2100 RT-70W
Cherry Hill, NJ 08002
Odd numbered months noon
Even numbered months 7pm

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
e-mail: RFSPC8@gmail.com
Chair: Amy Kiger

Meets second Thursday of each month
7:00 p.m.-8:30 p.m.

9 ATLANTIC

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

Meeting times and dates TBD
Arc of Atlantic County
6550 Delilah Rd., Suite 101
Egg Harbor Twp., NJ 08234

10 CAPE MAY

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

Contact the Regional Planning Support Council Chair for more
information about attending a meeting.



Time to Ration Health Care, What Will People with Disabilities Receive?

HEALTHCARE

By S. Paul Prior, Esq. & Maria Fischer, Esq.

As the sun beams through the window on a beautifully warm spring day, doctors at the regional medical center are dealing with three new critically ill COVID-19 patients. An otherwise healthy 35-year-old parent of 2 young children. A successful 45-year-old Wall Street executive. A highly decorated 38-year-old Special Olympics athlete with Down Syndrome and who is also a beloved employee at a local retail establishment. All three are now in respiratory distress and will soon require a ventilator to breathe. The hospital's exhausted ICU doctors turn to look at each other with agony in their eyes and despair on their faces because they know the hospital only has two ventilators available and they must decide: "Who will...."

We all watch as the number of reported COVID-19 cases rise. We all watch as the

number of reported COVID-19 deaths rise too. At some point in all this, although we are not sure when, "flattening the curve" has become a common phrase in our lives. We learn of news accounts from around the world where health care is rationed, patients triaged, and harsh bright line criteria are used to decide who gets treated...and who is left to die. We watch doctors and governors beg for ventilators on national television. We shake our heads and say to ourselves, "they can't possibly ration healthcare here" and we hope and pray we are right.

In the meantime, states are beginning to develop disaster preparedness plans and doomsday scenarios with respect to dispensing limited healthcare resources as cases continue to climb.



NEW JERSEY
REGIONAL
FAMILY SUPPORT
PLANNING COUNCILS

ARE YOU THE FAMILY MEMBER
OF A PERSON WITH DEVELOPMENTAL DISABILITIES?

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 providers 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 

Where will people with disabilities be counted in this process?

Worse yet: what if they are not?

This spring, the United States Department of Health and Human Services (HHS), Office for Civil Rights (OCR) issued a bulletin reminding officials and covered entities, like health care providers, of laws prohibiting discrimination on the basis of race, color, national origin, disability, age, sex, and religion. According to OCR such anti-discrimination provisions apply to the provision of health care services during COVID-19. Accordingly, people with disabilities cannot be denied medical care based on stereotype or a subjective assessment of the quality of a person's life. Treatment decisions must be made on objective medical criteria only.

However, some State plans indicate, "persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support." While such provisions are clearly illegal, we cannot allow such explicit or implicit language to find its way into New Jersey's Bioethics Plan. Our founding partner, Herb Hinkle, argued leading bioethics cases in the courts and served as a consultant to New Jersey's Bioethics Commission.

It is important for parents, families and disability advocates to be heard—and heard quickly because no one has the luxury of time right now. We must demand policymakers include language in whatever plan is ultimately developed which specifically prohibits the consideration of disability, stereotyped utilitarian assessments, or other discriminatory factors when making difficult health care decisions. We must say to our policymakers and government officials:

"Don't leave us behind." "Don't give up on us." "Our lives matter."

—S. Paul Prior, Esq.
—Maria Fischer, Esq.

Both writers are partners at Hinkle, Prior and Fischer, Attorneys at Law. Both have a family member with a developmental disability. P&F



SEVA
Special Education
Volunteer Advocates
www.spanadvocacy.org/SEVA
Supporting & Empowering Parents on Their Advocacy Journey

WHY SEVA?

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



SEVA Provides

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



Contact Jeannette to learn more:
jmejias@spanadvocacy.org





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



The Arc of NJ awardees during the 70th Anniversary Celebration. Front row, l-r: Joanne Bergin, President, The Arc of NJ; Linda Cancro Lucas, CEO, The Arc of Essex (Martin Papish Award); Evelyn Ramundo, President, The NJ Statewide Self-Advocacy Network (Bill Sackter Award)
Back row, l-r: Thomas Baffuto, Executive Director, The Arc of NJ; Todd Polyniak, Partner, Sax LLP (President's Award); Ralph Mas-trangelo (Volunteer of the Year); Vito Gagliardi, Esq., Managing Principal, accepting for The Porzio Family of Companies (Community Impact Award); S. Paul Prior, Esq., Hinkle, Prior and Fischer Attorneys at Law (Advocacy Matters Award)