



NJCDD's Eye on Advocacy weekly e-newsletter is published every Tuesday, focusing on important news and events for the intellectual and/or developmental disabilities community. You are welcome to submit news items and feedback to [njcdd@njcdd.org](mailto:njcdd@njcdd.org)

[Subscribe to NJCDD's Publications](#)



## 22q Awareness Month What is 22q?

**22q11.2 Deletion Syndrome: The most common genetic condition no one's talking about.**

22q11.2 Deletion syndrome or 22qDS (also referred to as Velocardiofacial syndrome (VCFS), and/or DiGeorge syndrome) affects multiple systems and is caused by a small missing piece of the 22nd chromosome. This tiny missing portion of chromosome 22 can affect every system in the human body. 22qDS can be the cause of nearly 200 mild to serious health and developmental challenges in children, with varying severity. It is oftentimes not diagnosed or recognized for years as the cause of these differences because each person diagnosed with 22qDS presents a unique set of the possible symptoms. This knowledge has yet to catch up to the general public or health care professionals. This leads many to believe the 1 in 2000 to 4000 estimated number of children born each year with 22qDS, is likely a gross underestimation of the actual numbers.

[Learn More](#)

## Upcoming Events

For more details on the events listed in this issue, scroll down

- Accessing Information for You or Your Loved Ones with Disabilities Nov. 18: [Register Here](#)
- From Vision to Action: New Jersey's Age-Friendly Journey Nov. 19: [Register Here](#)
- The Boggs Center Training: [Register Here](#)
- The Boggs Center Lecture Series: [Learn More](#)

**NEW JERSEY REGIONAL FAMILY SUPPORT PLANNING COUNCIL #1**  
Sussex, Warren, Morris

# Accessing Information for You or Your Loved Ones with Disabilities

**NOVEMBER 18, 2025**  
**7:00PM - 8:00PM**  
**VIRTUAL EVENT**

In collaboration with  
**PAUL ARONSOHN**  
New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

### Accessing Information for You or Your Loved Ones with Disabilities

Organizing services and supports that work for you or your loved ones with disabilities is an achievable goal, but what happens when they are not working? How do you get information, support, and advocacy when needed?

Plan ahead and be prepared by joining this listening and learning session with New Jersey's Ombudsman for People with Intellectual and/or Developmental Disabilities and Their Families: Paul Aronsohn.

Multi-lingual closed captioning is available for this event. Contact Kerry McGrath at [kerry.mcgrath@njcdd.org](mailto:kerry.mcgrath@njcdd.org) or 609-984-4516 if you have any questions.

[Register for This Event](#)

[Download Flyer](#)

## From Vision to Action: The Age-Friendly NJ Journey



**Friday, November 21st  
11am to 1pm**

Join us for a virtual gathering on November 21, 2025, to celebrate the progress of New Jersey's Age-Friendly efforts and the successes during the Murphy Administration! Hear from Age-Friendly grant recipients and enjoy a panel discussion on how leaders and community partners can build on this progress in the years to come. Don't miss it!

Click here  
to register  
for the  
event



To register for the event, go to the following URL:  
[https://dhs-nj.gov/zoomgov.com/webinar/register/WN\\_KCC6-Z\\_1QxethLGBJD1og](https://dhs-nj.gov/zoomgov.com/webinar/register/WN_KCC6-Z_1QxethLGBJD1og)

## From Vision to Action: New Jersey's Age-Friendly Journey

**Friday, November 21st  
11am to 1pm**

Join us for a virtual gathering on November 21, 2025, to celebrate the progress of New Jersey's Age-Friendly efforts and the successes during the Murphy Administration! Hear from Age-Friendly grant recipients and enjoy a panel discussion on how leaders and community partners can build on this progress in the years to come. Don't miss it!

[Register Here](#)

NEW JERSEY HUMAN SERVICES



The Boggs Center offers training and consultation on topics relevant to addressing the needs of and supporting people with developmental disabilities and families across the lifecycle.

You may view and register for many of these trainings using [The Boggs Center Online Registration System](#).

Learn more about Boggs Center training and consultation opportunities:

**Ageing & Grief**  
**Behavior & Mental Health**  
**Community Supports & Quality**  
**Community-Based Instruction**  
**Employment**  
**Meaningful Days**  
**PCAST - Person-Centered Approaches in Schools and Transition**  
**People With DD And Families**  
**Supports Brokerage**  
**Support Coordination**  
**Transition**  
**Workforce Development & Frontline Supervisors**

[Learn More](#)

# Developmental Disabilities Lecture Series

## FALL 2025 WEBINARS

**Registration is open for the Fall 2025  
Developmental Disabilities Lecture Series.**

[View Fall 2025 Developmental Disabilities Lecture Series Brochure](#)

[Learn More](#)

*All sessions will be held online using The Zoom Webinar platform.*



## Fiscal Intermediary (FI) Transition Update

The transition of the Division of Developmental Disabilities' (DDD) Vendor Fiscal/Employer Agent (VF/EA) Self-Directed Services Model from Public Partnerships LLC (PPL), the current fiscal intermediary, to Acumen Fiscal Agent (Acumen), is underway.

[Learn More on Upcoming Transition Webinars](#)

## In the News



New Jersey disability ombudsman Paul Aronsohn, during a tour of a group home in 2019. © Chris Pedota, NorthJersey.com-USA Today Network

## Rep. Tom Kean pushes for national disability ombudsman, modeled after NJ watchdog

*Story by Gene Myers, NorthJersey.com*

U.S. Rep. Tom Kean Jr. is developing federal legislation to create the nation's first ombudsman for people with disabilities, much like the watchdog office he helped establish in New Jersey in 2018.

Speaking at the October meeting of the New Jersey Legislative Disability Caucus, the Republican congressman said his staff "is currently working on legislation that would establish a national intellectual and developmental disabilities ombudsman," modeled after the state's version and the existing federal long-term care ombudsman.

[Read More](#)



New Jersey Democratic gubernatorial candidate Mikie Sherrill speaks at her rally during a campaign event, Saturday, Nov. 1, 2025, in Newark, N.J. (AP Photo/Angelina Katsanis)

## Congratulations Governor-Elect

Congratulations to Mikie Sherrill, New Jersey's Governor-elect. NJCDD looks forward to working together with the new administration to support the needs of individuals with intellectual and developmental disabilities and their families.

Last week, NJCDD, the NJ Regional Support Planning Council, and the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families submitted a memo to Governor-elect Sherrill outlining a blueprint for safe, high-quality residences for individuals with disabilities residing in state-licensed settings.

[Read the memo](#)

# Hurdles to Health Care Series by northjersey.com



Dr. Larry Rosen

[Read More](#)

## How the next generation of NJ doctors is improving care for people with disabilities

Story by Gene Myers and Scott Fallon, NorthJersey.com

When Elizabeth Dalzell's daughter Liesl complained of severe pain in her left shoulder in June by using sign language, it began a nearly monthlong [odyssey through New Jersey's health care system](#) before the young woman with multiple disabilities received the care she needed — a routine cortisone shot.

During that time, an urgent care provider balked at giving Liesl an X-ray because she moved too much. An orthopedist asked Dalzell if her daughter would get "all weird" during an examination. And a week had to pass before an anesthesiologist was available to put Liesl under so she could receive the shot without interfering.



Ed Heaton

[Read More](#)

## NJ man with disability hit with \$3,390 ambulance bill Horizon refused to cover

Story by Gene Myers and Scott Fallon, NorthJersey.com

Days after Ed Heaton had surgery to repair his broken shoulder in May 2023, he was transported from a rehab facility in Essex County to his surgeon's office for an exam.

Because Heaton has cerebral palsy and is paraplegic, his rehab facility had booked an ambulance so he could more easily be transferred from a bed to a gurney.

Moving him onto his medical scooter using a small crane called a Hoyer Lift and into an ambulance van would have been excruciatingly painful after surgery.



[Read More](#)

## Beyond the ramp: These New Jersey clinics are redefining disability access in health care

Story by Gene Myers and Scott Fallon, NorthJersey.com

The front entrance now includes a ramp. The exam room has a height-adjustable table and transfer board. If the waiting room is too loud, patients can go outside.

None of this happened by accident. It came from listening.

At the Freehold Family Health Center, a patient advisory council of people with disabilities, caregivers and health care professionals mapped the barriers preventing access to the clinic and then took steps to fix them — from re-stripping the lot for more accessible parking to moving a curb cut, adding equipment and providing more training.



Josh Gargano

[Read More](#)

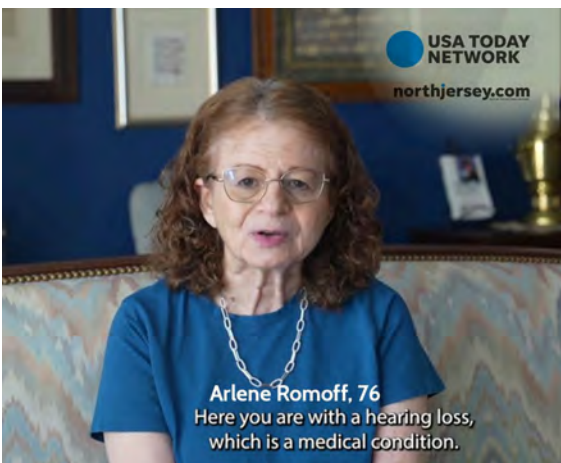
## In NJ, managed care means delays and denials for disabled patients: 'Not a fair fight'

Story by Gene Myers and Scott Fallon, NorthJersey.com

Josh Gargano knew what would happen when his therapy was cut.

His body would seize up. Without regular physical and occupational therapy, his spastic quadriplegia — a severe form of cerebral palsy — would lead to increased stiffness, reduced mobility and, eventually, chronic pain.

"You take these services away, I regress," said Gargano, 35, who uses a wheelchair. "You put me back on them, I improve. It's as simple as that."



Arlene Romoff, 76  
Here you are with a hearing loss, which is a medical condition.

[Read More](#)

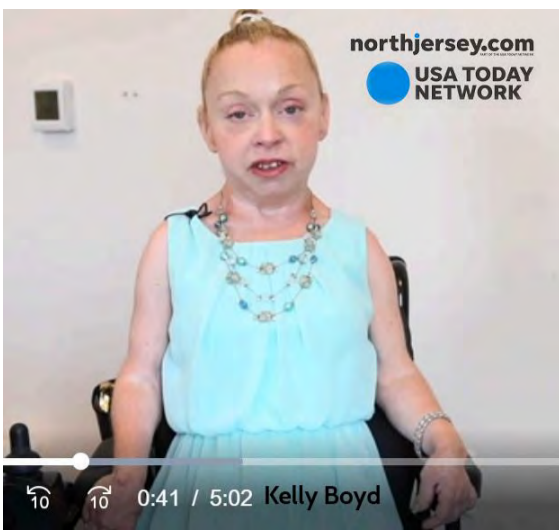
## NJ's health system has a huge gap in care for people with disabilities on Medicaid

Story by Gene Myers and Scott Fallon, NorthJersey.com

When Nantanee Koppstein found a new primary care nurse practitioner for her daughter, she was overjoyed — considering that it took weeks of searching for a doctor who had experience treating a patient with developmental disabilities.

The first visit was great. The doctor was kind and competent. Koppstein and her daughter, who has multiple disabilities, were confident they had found a practice that would serve them for years.

But a few weeks later, in early 2020, Koppstein's hopes came crashing down.



## In NJ, people with disabilities face indignity, missed diagnoses, barriers to health care

Story by Gene Myers and Scott Fallon, NorthJersey.com

Kelly Boyd, 45, remembers a trip to a Mercer County OB/GYN not for what the doctor did, but for what she said.

"She asked me — twice — if I was a dwarf," Boyd said.

The doctor hadn't read her chart, which noted her diagnosis of rheumatoid arthritis, a condition she has battled since infancy. The Hamilton Township resident, who uses a wheelchair and is 4-foot-9, said the question was offensive — and irrelevant.

[Read More](#)

# Resources

**Supports Brokers**  
Assisting and Empowering You to Self-Direct

**Getting Started**

In New Jersey, people can self-direct all or some of their Home and Community Based Services, made available through the Division of Developmental Disabilities (DDD) Supports Program or Community Care Program. Self-directed services are provided by a person you hire, known as a self-directed employee (SDE), or a service provided by a business/vendor that serves the general public, and are paid through use of a fiscal intermediary. Your Support Coordinator will work with you and, as needed, your family to help you understand what it means to self-direct by sharing information, as well as:

- Talking with you to learn about your strengths, needs, and interests, and what you want and don't want in your life
- Supporting you to describe your life goals
- Identifying different types of support that can be used to help you achieve your life goals, including DDD services, relationship-based supports (such as a family member or neighbor), community resources, technology, and other state and local service systems
- Explaining how self-directed services are different from provider-managed services, and which DDD services can be self-directed and which cannot
- Describing the role of the fiscal intermediary and the differences between the two options - Agency with Choice and Vendor Fiscal/Employer Agent
- Sharing information about the resources you use when you self-direct one or more of your services

A fiscal intermediary will be used to process payment and assigned tasks related to your approved self-directed services.

When you choose to self-direct, you can hire a Supports Broker.

**Supports Brokerage** is a service that is available in the DDD Supports Program and Community Care Program. Your Support Coordinator can help you to identify a Supports Brokerage agency. A **Supports Broker** can help you coordinate and maintain your self-directed services. They empower you to take control of your self-directed services, grow community connections, and direct the life you want.

**Learn More**

- Check out **Understanding Self-Directed Services in New Jersey** by the Boggs Center: <https://boggscenter.org/subsites/edu/resources/publications/understanding-self-directed-services-in-new-jersey-and-the-role-of-the-supports-broker/>
- Visit the **Office of Education on Self-Directed Services webpage**: <https://www.nj.gov/education/office-of-education/community/schools/>
- Email DDD.OCESD@dnj.nj.gov

**RUTGERS HEALTH**  
The Boggs Center on Disability and Human Development  
Robert Wood Johnson Medical School

**DDD** Division of Developmental Disabilities



## Supports Brokers: Assisting and Empowering You to Self-Direct

In New Jersey, people can self-direct all or some of the Home and Community Based Services, made available through the Division of Developmental Disabilities (DDD) Supports Program or Community Care Program. Supports Brokers can help people who choose to self-direct to coordinate and maintain their self-directed services. The Boggs Center is excited to share **Supports Brokers: Assisting and Empowering You to Self-Direct**, a new one-page fact sheet to help people with disabilities and families better understand self-direction and the roles and responsibilities of Supports Brokers.

[Download Fact Sheet](#)

Need help with child care, child support, food assistance or cash assistance?

**The Division of Family Development can help!**

## Division of Family Development

The Division of Family Development (DFD) is the state agency that supervises four programs that support New Jersey Families. Use the links below to navigate to the service you are looking for.

**The Child Care Assistance Program** can help lower-income families who are working, in training or in school, or a combination of these activities to pay a portion of their child care.

[Get help paying for, or finding, childcare in NJ](#)

**The New Jersey Child Support Program** helps establish and enforce child support orders, locate parents, establish paternity, and provide options for paying support.

[Learn more about Child Support](#)

**NJ SNAP** is the food assistance program that helps low-income individuals and families buy the groceries needed to eat healthy.

[Learn more, and apply, for food assistance](#)

**WFNJ** provides temporary cash assistance and many other support services through the Temporary Assistance for Needy Families (TANF) program for families and General Assistance (GA) for single adults and couples without children.

[Learn more about WFNJ cash assistance](#)

**VOTING:**  
IT'S YOUR RIGHT

## Voting: It's Your Right

Voting: It's Your Right is a guide about voting rights and the voting process in New Jersey written in clear language for people with intellectual and developmental disabilities. The 7th Edition, available electronically in English and Spanish, provides readers with information on:

- Registering and preparing to vote
- Options for voting by mail and in-person
- Voting rights and accessibility
- Contacting election officials with questions

[Download guide – English](#)

[Download guide – Spanish](#)

Limited quantities are available in hard copy format through the Publications Order Form.

[Access the Order Form Here](#)

Voting: It's Your Right is also available as an [E-Learning course](#)



**Selecting a Service Provider**  
**Making Choices, Becoming Empowered**  
 A Guide for People with Disabilities and Their Families

People receiving services through New Jersey's Division of Developmental Disabilities (DDD) can choose the service provider that best meets their needs. This guide offers people with disabilities and their families ideas that can help them select a provider that will support them to live the lives they want.

**RUTGERS HEALTH**  
**The Boggs Center**  
 on Disability and Human Development  
 Robert Wood Johnson Medical School

## Selecting a Service Provider: Making Choices, Becoming Empowered

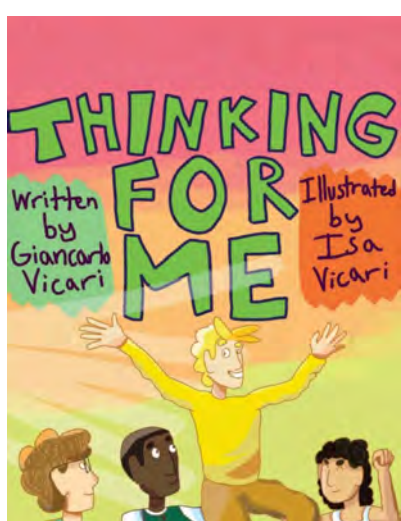
People receiving support through New Jersey's Division of Developmental Disabilities can choose the service provider that best meets their needs. This guide offers people with disabilities and their families ideas that can help them select a provider that will support them to live the lives they want.

[Download guide – English](#)

[Download guide – Spanish](#)

Limited quantities are available in hard copy format through the Publications Order Form.

[Access the Order Form Here](#)



## Thinking for Me Comic

[Learn More](#)

Giancarlo Vicari, Youth Ambassador from New Jersey, created a comic called "Thinking for Me" about turning 18 and talking to your parents about alternatives to guardianship. We helped make Giancarlo's comic into a 5-minute audio story narrated by Giancarlo and his friends. This audio story is a great resource to share with anyone interested in learning more about supported decision-making and alternatives to guardianship!

[Download the Comic](#)



**Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families**

## Transition Resources New Jersey State Resources

One challenge common to every individual with an intellectual or developmental disability and their families is the transition from childhood to adulthood. Known as the proverbial "cliff" – the point at which there seems to be a sudden drop in services and supports as children age out of the school system and into adult life. Below are resources to help with this transition.

[Learn More](#)

## Jobs that Care New Jersey

**Looking for employees?**  
 Learn how to find employees in your area.

[LEARN MORE](#)

The Direct Care and Service Workforce is critical to the lives of people with disabilities and those who are aging. The demand for these jobs is growing fast and will continue to increase in years to come. This workforce is essential to providing the supports individuals need to live healthy, active, and engaged lives in the community. From helping with personal, health, and home care to providing support with community activities, workers in these roles make a difference!

If you are interested pursuing a rewarding career, please check out the information on this site to learn more and to find jobs in your area.

[Learn More](#)



## Employment First

The Employment First page on the NJCDD website has been updated with information intended for individuals living with disabilities who are interested in working!

Now, along with information about Employment First in New Jersey, the page features plain language information and links related to:

- [Seeking Employment](#)
- [Benefit Resources](#) as they relate to work
- [Transitioning to employment](#) from high school

[Learn More](#)

**DISABILITY BENEFITS 101 NEW JERSEY**  
[HTTPS://NJ.DB101.ORG](https://nj.db101.org)

- + FIND THE RIGHT HEALTH COVERAGE FOR YOU
- + BENEFITS AND WORK ESTIMATOR
- + LEARN ABOUT SSI & SSDI BENEFITS, AND MORE!



**BENEFICIOS POR DISCAPACIDAD 101 NUEVA JERSEY**  
[HTTPS://NJ.DB101.ORG](https://nj.db101.org)

- + ENCUENTRE EL SEGURO MÉDICO A SU MEDIDA
- + ESTIMADOR DE BENEFICIOS Y TRABAJO
- + CONOZCA LOS BENEFICIOS DE SSI Y SSDI, ¡Y MÁS!

The NJCDD is proud to support NJ DB101, a free, user-friendly, all-in-one place, resource guide for employment and benefit questions/information. Find out how working impacts benefits like SSI, SSDI, Medicaid, and more! Resources are in plain language and available in both [English](#) and [Spanish](#).

[Learn More](#)

# An Enhanced Family Support Crisis Handbook

4th Edition

Available in English and Spanish



## Enhanced Family Crisis Handbook

The purpose of this expanded version of the Toolkit is to empower individuals with disabilities and their family and professional caregivers by providing information to more effectively advocate for persons with complex severe behavioral health conditions (which we formerly referred to as “dual diagnosis”) for treatments, supports, services and the conditions that promote mental wellness.

[Learn More](#)

## Manual Mejorado de Crisis Familiares

El propósito de esta versión ampliada del kit de herramientas es facilitarles a las personas que tienen discapacidades y a sus cuidadores familiares y profesionales herramientas que los empoderen, al proveer información que permita abogar de una forma más efectiva por las personas que tienen condiciones graves y complejas de salud conductual (a las que antes se denominaban con “diagnóstico dual”) para conseguir los tratamientos, apoyos, servicios y las condiciones que fomentan el bienestar mental.

[Aprende Más](#)



20 West State Street, Trenton, NJ, 08608 | [Preference Manager](#) | [Unsubscribe](#)

Telephone: 1-800-792-8858 | Email: [njcdd@njcdd.org](mailto:njcdd@njcdd.org)

**NJCDD Disclaimer:** New Jersey Council on Developmental Disabilities does not endorse or recommend any programs, providers, or organizations. This is for information-sharing purposes only.