CARLY HEWITT
Following Her Dream
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.

NJCDD.org | Kyoko Coco | 609-341-3112 | kyoko.coco@njcdd.org

www.facebook.com/NJFSPC

Supported by the New Jersey Council on Developmental Disabilities
The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

Subscriptions to People & Families are free and are available through the Council office or by e-mail at njcdd@njcdd.org. Please include your name and address. Articles may be reprinted without fee by permission. Expressed opinions are not necessarily those of the Council’s membership. We welcome your letters and comments. Send them to Jonathan Waller, editor, NJCDD, PO Box 700, Trenton, NJ 08625-0700. Please include your name and town. Letters may be reprinted and edited for space.

New Jersey Council on Developmental Disabilities, PO Box 700, Trenton, NJ 08625-0700. TELEPHONE: 609.292.3745 TDD 609.777.3238 FAX 609.292.7114 E-MAIL njcdd@njcdd.org INTERNET www.njcdd.org
Letters from the Executive Director

In the Instance of School Violence…

After a tragedy like the one at Marjory Stoneman Douglas school earlier this year, many of us search for clues as to how someone could carry out such violent acts. Is it the over-availability of deadly firearms? Violent video games? Social isolation? Troublingly, certain “experts” on cable news will stress that perpetrators are “loners” or “odd”, implying they have mental illness or autism disorders. Yet research shows that people with mental illness or autism are far more likely to be the victim of violence than the culprit.

News & Notes

Employment for Americans With Disabilities Reaches 2-Year Milestone
- Lawmakers Band Together to Defend ADA
- Mom of Girl with Learning Disability Had an Incredible Epiphany
- Students with Special Needs Face Suspension After School Shooting
- Judge Says NJ Towns Must Allow Affordable Housing, Maybe More than 15,000 New Units
- Upcoming Events

New DHS Commissioner Seeks to Identify Barriers and Improve Access to Care and Services

On April 2, Carole Johnson was sworn in as Commissioner for the New Jersey Department of Human Services, adding to an accomplished career that includes five and a half years serving in President Barack Obama’s White House as a senior health policy advisor. As she begins her tenure at DHS, the new commissioner has two prevailing goals: Identify and address barriers to accessing care and services, and Ensure DHS is as user-friendly as possible.

Information About Family Support

School Safety in the 21st Century

Amid growing anxiety among parents, lawmakers, and educators relating to school safety and crisis management, it is critical to consider that children with physical, intellectual, and behavioral impairments require additional support and accommodations in the event of a school-wide emergency. Fortunately, with planning and forethought, school personnel and parents can take steps to ensure that all students are kept safe.
#METOO
Abuse and Exploitation of People with Developmental Disabilities

Recently, the #MeToo movement has brought awareness of sexual harassment, abuse, and exploitation to the national discourse. With this has come increased support to victims and access to resources for healing. But there is a group of victims whose stories have yet to be told: those with developmental disabilities.

COVER STORY
CARLY HEWITT
Following Her Dream

Pursuing a college degree, maintaining a social life, and planning for the future can be a challenging for most of us. And prior to obtaining assistive technology through Advancing Opportunities, 23-year-old Carly Hewitt found it quite daunting. With developmental disabilities that affect all of her muscles, Carly requires hands-free mobility and communication tools that will work reliably without slowing her down. Since she discovered “eye-gaze” technology, Carly has been able to access pathways to independence and success like never before.

ADDRESSING CHALLENGING STUDENT BEHAVIOR IN SCHOOLS
New Jersey’s New Law on Seclusion and Restraint

New Jersey has recently passed new legislation to regulate the use of seclusion techniques and physical restraint procedures on children and teens with disabilities. The disability community is divided in its view of this new bill, with Autism New Jersey and The Arc of New Jersey in favor, and children advocacy organizations including the Statewide Parent Advocacy Network in strong opposition. But the issues and challenges around Seclusion and Restraint are nuanced.

Front Cover
Carly Hewitt (left) with her mother Lori (right) at their home in Sayerville, NJ:
—Photo by Rebecca Shavulsky
In the Instance of School Violence, Students with Autism or Mental Illness Are More Likely to Be Victims Than Perpetrators

Like so many, my heart is broken for each of the school communities that have been affected by gun violence. It is impossible to make sense of a school shooting, but they have become our new “normal”: in the first 11 weeks of 2018, there were 17 school shootings in which someone was hurt or killed, and the list grows. It is tragic and terrifying, and it demands response.

“What would make someone do that?”

Inexplicable violence feels harder to accept. It makes us feel even more vulnerable. In an effort to find a solution, it is natural to look for a cause. Is it the sheer number of guns? Is it easy access to military-style assault weapons? Is it the age at which someone can buy a gun? Bump stocks? Violent video games? Is it lax mental health laws? Inadequate mental health services? School bullying? School security? The quest for notoriety in an era of the 24-hour news cycle?

Self-appointed experts are often quick to describe the teens and young adults who commit these violent acts as “odd” and as “loners,” leaping to the suggestion that they have autism spectrum disorders (ASD) or severe mental illness, even if there is no evidence for this. Researchers have cautioned against sweeping conclusions and causality: neurodevelopmental disorders do not portend mass murder.

One thing that is NOT a cause of school shootings is autism, mental illness or other disabilities. In fact, a 2017 study found no evidence to suggest that people with ASD are any more violent than those without ASD. In reality, individuals with mental illness or intellectual/behavioral impairments like autism are far more likely to be the victim of a violent crime than perpetrators of violence.

The data show the sheer number of guns correlated with gun violence and the rate of gun deaths. While no exact counts exist, experts believe there are more than 300 million guns in our country, held by 1/3 of Americans. There are only about 74 million children, so guns outnumber kids 4 to 1. When it comes to gun ownership and deaths by guns, no one can dispute the numbers—America is an outlier.

That said, there are undoubtedly severe symptoms and events—“red flags”—that can make a person more vulnerable to committing violent acts. However, that can’t and shouldn’t give us license to stigmatize entire groups of people.

In a statement, the Autism Society of America said, “To imply or suggest that some linkage exists is wrong and is harmful to more than 1.5 million law-abiding, nonviolent, and wonderful individuals who live with autism every day.”

As the saying goes, “if you know one person with autism, you know one person with autism,” so I hesitate to make generalizations. That said, most of the people with autism I know are deeply sensitive, ethical individuals, who are sometimes misunderstood, and who struggle to gain the supports they need to live an everyday life. The same goes for people with mental illness and other disabilities.

We all want to know “why,” because then we would know what to do to bring school shootings to an end. But the answer does not lie in further stigmatizing people with autism and other disabilities in ways that make them scapegoats for the unexplained. To do so will not reduce gun violence in any way.

For further reading:
http://psycnet.apa.org/record/2016-61678-005
East Hanover, NJ—Americans with disabilities reached a milestone this month, as the major economic indicators showed increases for the 24th consecutive month, according to today’s National Trends in Disability Employment - Monthly Update (nTIDE), issued by Kessler Foundation and the University of New Hampshire’s Institute on Disability (UNH-IOD).

The strengthening economy underscores the value of diversity in the workplace. As hiring increases, preparing for the workplace is more important than ever for people with disabilities. Jobseekers with skills and experience gain employment more readily. Programs that provide hands-on work experiences are equipping people with disabilities with the skills they need to succeed in careers in government, nonprofits and private industries.

In the Bureau of Labor Statistics (BLS) Jobs Report released Friday, April 6, the employment-to-population ratio for working-age people with disabilities increased from 28.6 percent in March 2017 to 31.7 percent in March 2018 (up 10.8 percent; 3.1 percentage points). For working-age people without disabilities, the employment-to-population ratio also increased from 73.3 percent in March 2017 to 73.6 percent in March 2018 (up 0.4 percent; 0.3 percentage points). The employment-to-population ratio, a key indicator, reflects the
percentage of people who are working relative to the total population (the number of people working divided by the number of people in the total population multiplied by 100).

“For the 24th consecutive month, we are seeing improvement in the employment-to-population ratio for people with disabilities, commented John O’Neill, PhD, director of employment and disability research at Kessler Foundation. “This is the longest duration of job gains we’ve seen during our five years of issuing nTIDE Jobs Reports. Most importantly,” he emphasized, “because of this upward trend, people with disabilities are closing in on their pre-Great Recession employment levels.”

The labor force participation rate for working-age people with disabilities increased from 32.3 percent in March 2017 to 34.8 percent in March 2018 (up 7.7 percent; 2.5 percentage points), while for working-age people without disabilities, the labor force participation rate increased slightly from 76.6 percent in March 2017 to 76.7 percent in March 2018 (up 0.1 percent; 0.1 percentage points). The labor force participation rate is the percentage of the population that is working or actively looking for work.

“The gains made by people with disabilities continue to outpace the gains of people without disabilities,” said Andrew Houtenville, PhD, associate professor of economics at UNH and research director of the Institute on Disability. “The recent increases in wages may possibly be offsetting some of the barriers that people with disabilities face, and thus making employment more feasible,” he noted.

For students, internships are a proven pathway to competitive employment. The Washington Center for Internships and Academic Seminars (TWC) connects college students from the U.S.
and abroad with semester experiences for academic credit in the DC area. TWC actively recruits students with disabilities and provides comprehensive support services to ensure their full participation in the internship program. Through its Leadership Initiative for Student with Disabilities, TWC supports scores of students every year, enabling them to choose from the rich array of opportunities in our nation’s capital, while employers meet potential job candidates and learn the benefits of workplace inclusion.

New Jersey college students are eligible for TWC scholarships funded by Kessler Foundation. “The internship experience is especially valuable for students with disabilities,” said Elaine E. Katz, MS, CCC-SLP, senior vice president of grants and communications at Kessler Foundation. “Like other students, they gain skills and experience and earn course credit. However, effectively managing their disability in workplace requires that they have knowledge of their rights as employees. At TWC, students with disabilities receive the preparation they need to launch themselves into the workplace and navigate their advancement in professional careers.”

In March 2018, among workers ages 16-64, the 4,945,000 workers with disabilities represented 3.4 percent of the total 145,299,000 workers in the U.S.

The next nTIDE will be issued on Friday, May 4, 2018.

Note that each nTIDE is followed by a noon webinar that features our experts, as well as invited panelists to discuss current disability-related findings and events. You can join live or watch the recordings at: http://www.ResearchonDisability.org/nTIDE.

NOTE: The statistics in the nTIDE are based on Bureau of Labor Statistics numbers, but are not identical. They are customized by UNH to combine the statistics for men and women of working age (16 to 64). NTIDE is funded, in part, by grants from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) (9ORT5022 and 90RT5017) and Kessler Foundation.
Lawmakers Band Together to Defend ADA

By: Michelle Diament
From: DisabilityScoop.com—April 4, 2018

U.S. Senate Democrats are vowing to block legislation that would dramatically alter the Americans with Disabilities Act.

A letter signed by 43 Democratic senators urges Senate Majority Leader Mitch McConnell, R-Ky., not to bring forward a bill known as the ADA Education and Reform Act, or H.R. 620.

The measure, which was approved by the House of Representatives in February, would require individuals who experience accessibility barriers at public businesses to submit written notice of the issues. Then, businesses would have up to 60 days to respond and another 60 days to start improvements.

Proponents of the legislation say that it would protect businesses from opportunistic lawsuits while giving proprietors time to correct problems.

Disability advocates counter, however, that businesses have had more than two decades to comply with the ADA and the proposed changes to the law would leave people with disabilities unable to access stores, restaurants, movie theaters and other spaces for months after flagging an accessibility violation.

“No American should be forced to endure discrimination for any length of time so that places of public accommodation may learn how to follow a seminal, bipartisan civil rights law that was enacted in 1990,” reads the Democrats’ letter sent to McConnell late last month. “Respectfully, we urge you to join us in supporting the rights of Americans with disabilities by making clear that H.R. 620, or similar legislation, will never receive a vote in the United States Senate during the 115th Congress.”

Since the bill passed the House, Senate leaders could choose to consider it at any moment. The Democrats say that if the bill is brought up, they will block it.

“We haven’t gotten any indications on timing, but since the Senate majority leader has the ability to bring it up for a vote anytime, Sen. Duckworth felt it was important to organize a filibuster-proof coalition of senators in opposition to the bill to make sure he understood it could not pass,” Sean Savett, a spokesman for the letter's organizer, Sen. Tammy Duckworth, D-Ill., told Disability Scoop.

A representative for McConnell did not respond to questions about the letter or the bill.
When school authorities tell a single mother of two that they “aren’t required to assist” her 6-year-old daughter with special needs, what is a mother to do? One particular mother decided to become an authoritative figure of her own organization and help her daughter in her own special way.

Jaye Wilson; a self-driven mother of two young girls ages 6 and 9, drives her family around town on a crisp spring day, chuckling at a joke her daughter made during our phone interview. Animated and exuberant, Jaye’s youngest daughter Ava can be heard in the back of the car squealing in delight as she plays with her sister, Nadiyah. Only Ava wasn’t always the talkative young girl she is today—just seven months ago she hardly spoke at all.

“I think for me it was difficult to see [Ava] very withdrawn because she’s a very vibrant kid,” Jaye states somberly, recalling her daughter’s first year
in elementary school. Taking a deep breath, Jay continues: “But when she started school she was afraid to speak because she could hear that she sounded different.”

Unbeknownst to Jaye, the usually bubbly Ava would become bashful and reclusive when approached by other classmates at school. Internally tormented, Ava confessed she didn’t like going to school when prodded by her mother one day after school.

“I didn’t like it,” Ava would tearfully confess before going on to say “[the other children] didn’t even know what I was saying—I don’t want to speak all!”

Feeling frustrated, Jaye turned to her daughter’s school board of education for assistance with Ava’s developmental delays and learning disabilities, even writing a letter to the mayor of her town.

“I got nothing back in return, nothing,” Jaye says, her voice full of disappointment.

Having minimal support from her children’s father, and with extended family in an entirely different state, Jaye suddenly had an epiphany.

With personal funding, Jaye created a company called Melinated Moms—an organization set out to connect different single mother’s worldwide to support one another through social events, women empowerment seminars, and mommy and me gatherings.

With the support of other single mothers like herself, Jaye found that she no longer had to be alone and could confide in and lean on others, who in turn would do the same for each other.

Melinated Moms now has over 1,477 members, and not only provided ways to meet and support other women going through struggles of being an independent parent of a child with learning disabilities but led to acquiring different techniques to try with Ava with assistance from The Children’s Specialized Hospital.

“[The hospital] show me how to do certain verbal exercises with Ava, like position my mouth a certain way when sounding out certain words,” Jaye says with pride.

Within just nine months, Ava began to vocalize her words without struggle, and truly found her voice—Jaye even found a new school to for Ava to transition into with ease.

Jaye found that she owed a lot of Ava’s improvement to the constant support of the sisterhood of mothers in Melinated Moms, and assistance from The Children’s Specialized Hospital.

To pay it forward, Jaye decided to assemble her team of moms to participate in The Children’s Specialized Hospital’s 12th Annual Walk n’ Roll Charity Walk in New Jersey this upcoming May, to help raise money for over 30,000 children with health care needs; much like her own daughter’s just one year ago.

The charity walk encourages all invited to donate what they can and take a step towards aiding children affected by developmental disabilities. As for the best part of the charitable cause for Jaye?

“I am excited to be a part of this with [my] kids,” said Jaye. “It means a lot to know I can lean on so many other women as well—it keeps me motivated.”

Connect with Us on Social Media

“Like Us” on Facebook
www.facebook.com/NJCDD

Follow us on
Twitter@theNJCDD

Subscribe to
Our YouTube Channel
www.youtube.com/theNJCDD
Students with Special Needs Face Suspension After School Shooting

By: Megan O’Matz
From: The Sun Sentinel—March 30, 2018

FORT LAUDERDALE, Fla.—In the aftermath of the Parkland massacre, some students with disabilities are being taunted or callously pegged by others as being the next school shooter, parents and experts say.

“There’s been a lot of bullying going on in our schools,” said Kelly Busch, a South Florida advocate for children with autism.

School and mental health records show that Nikolas Cruz, who killed 17 and wounded 17 more at Marjory Stoneman Douglas High on Valentine’s Day, was reported to have numerous conditions, including autism and severe behavioral and emotional problems.

Slapping Cruz with a label of autism has increased the angst of parents of children with the disorder, who already struggle to foster acceptance and compassion for their children.
Experts say some people with autism, especially children, may find it hard to communicate or to control their emotions. They can experience “sensory overload,” or become frustrated when unable to express themselves and may become aggressive or irritated. Their outbursts—such as throwing a chair—occur in flashes, however, and typically are minor and over quickly. Premeditated acts of violence are not a symptom of autism.

Yet Valerie Herskowitz, of Jupiter, who has a grown son with autism, said she’s heard from parents that some students have asked children on the spectrum: “Are you going to kill us?”

Broward Schools Superintendent Robert Runcie said he’s seen no data or internal information showing any spike in bullying or unease regarding students with developmental disabilities.

“If it’s true that there are students in the school district being stigmatized because of their special need or disability, that’s something we’re not going to tolerate, and we’re going to take appropriate action to address,” Runcie said.

“I’m looking forward to hearing from our parents. Certainly we’ll do our own review based on what we hear from them about what is going on in the schools.”

The desire by advocates to clarify publicly that people with autism are not inherently violent is a direct response to reports that Cruz, now 19, had autism.

His mother told state social service workers in September 2016, shortly after he turned 18, that Nikolas had autism and attention-deficit hyperactivity disorder, which makes it difficult for people to pay attention and control impulsive behaviors, according to records from the Department of Children and Families.

An earlier 2014 school psychiatric report stated that Cruz struggled with anxiety, behavioral and socio-emotional problems, and was openly defiant of authority figures. It cited the need to rule out “pervasive developmental disorder,” which is an autism spectrum disorder.

His mother, who died only months before the shooting, also told Broward sheriff’s deputies that Nikolas had an obsessive-compulsive disorder and anger issues.

“He had many issues beyond autism,” and likely was a “very complex psychiatric case,” said Michael Alessandri, executive director of the University of Miami-Nova Southeastern University Center for Autism and Related Disabilities, which provides services to people with autism and resources for school districts.

Often when children have many and varying symptoms and numerous diagnoses it indicates that professionals are “not quite sure what the kid really has,” said Alessandri.

“It’s not about autism. It’s about a boy with a clearly demented mind, a lot of anger and a lot of horrible life circumstances—who harmed lots of people.”

Still, a few parents in South Florida have told the University of Miami center since the shooting that peers are bullying their children and that even some school officials are now reacting differently to certain behaviors than they had in the past, Alessandri said.

After the shooting a few children with autism across South Florida, Alessandri said, have been suspended and at least one was expelled from a private school for “a perceived threat” based on a wrestling video he made.

One child with autism, knowing Cruz possibly also had autism, was trying to process the shared condition and deal with his own anxiety over it by talking a little too much about the shooting—making his classmates and school personnel nervous, Alessandri said. The boy’s mother told Alessandri that school officials recommended he leave school temporarily to get care and treatment.
The day after the Parkland shooting, the Autism Society, a national advocacy group, released a statement saying: “No reliable research has found that a person who is autistic is more likely to commit violence than a person without an autism diagnosis. In fact, existing research finds that autistic individuals are more likely to be victims of violence than those without an autism diagnosis.”

The society put out a similar statement after the 2012 Sandy Hook elementary school shooting because that gunman, Adam Lanza, was diagnosed in his early teens with Asperger’s syndrome.
About 1 in 68 children has been identified with autism spectrum disorder, according to the most recent figures from the Centers for Disease Control and Prevention. It is more prevalent in boys than in girls.

Attorney Jeff Kasky of Delray Beach, whose son Cameron co-founded the #NeverAgain movement, has another child, Holden, who has autism. Both boys attend Marjory Stoneman Douglas High and were hiding in a classroom in the freshman building during the shooting. Later with his dad, Holden made a video discussing the shooting and his reaction to police who were shouting and “had a bunch of guns” and flashlights pointed at him and other students. The video urges law enforcement to take special care when responding to emergencies involving people with autism or other developmental disabilities, who may not properly respond to commands.

It’s been viewed on YouTube more than 80,000 times and 2.3 million times on Facebook. The video notes that Cruz reportedly had autism, but autism did not lead to the shooting. “Autism is not a violent disorder,” Jeff Kasky says in the video. “It’s quite the opposite; the things that caused violence in this person were all the other things that were going on in his sick mind.”

In a ruling that could shape the way towns across the state look and have an impact on schools and traffic, a Superior Court judge said Thursday that municipalities must take steps now that could allow for roughly 155,000 housing units to be built over the next decade.

The highly anticipated, 217-page opinion by Judge Mary C. Jacobson in Mercer County applies directly to two towns, Princeton and West Windsor, but it could set a precedent for more than 100 other municipalities that have gone to court to settle disputes over their affordable-housing obligations.

“Judge Jacobson’s decision recognizes the very substantial need for homes for working families and people with disabilities in New Jersey,” said Kevin Walsh, executive director of the Fair Share Housing Center, a nonprofit that argued on behalf of poor and middle-class families. “This ruling sends a strong message to any town still seeking to exclude working families that they won’t succeed.”

The statewide figure reached by Jacobson is not as high as some advocates had called for, but it also is not as low as what some local governments had sought. Suburban towns have long resisted New Jersey’s affordable-housing laws, which were meant to combat discriminatory zoning practices but have also raised concerns about congestion and property values.

“It’s still a challenging number to meet when you consider whether or not the market can sustain that level of growth going forward,” said Michael Cerra, assistant executive director of the New Jersey League of Municipalities, which has sought to limit towns’ obligations to build affordable housing.
affordable units. “It’s still going to require the Legislature and the administration to work with us and other stakeholders to develop a comprehensive statewide policy, which includes tools to comply and sufficient funding.”

Thursday’s decision is the first time a court has determined a municipal obligation since the state Supreme Court ruled last year that local governments faced a legal requirement to provide affordable housing for poor and middle-class families during a period from 1999 to 2015.

The Council on Affordable Housing, which was set up in 1985 to oversee the state’s affordable-housing program, was paralyzed during those years, and the Supreme Court eventually stepped in to order towns to sidestep the council and deal directly with the state courts.

More than 190 municipalities have already reached settlements that set their affordable housing obligations, according to the Fair Share Housing Center, while others are exempt because they are in urban areas or have environmental constraints.

For the remaining towns that are still in court or are yet to start the process, however, Thursday’s decision could be the “domino” that speeds settlements or other court decisions, Cerra said.

“I can assure you within the next 72 hours, every attorney for every municipality involved and every attorney involved on the developer side and advocate side are going to be reading this decision to figure out what their next steps are,” he said.

Walsh said the Fair Share Housing Center had not yet decided whether to appeal parts of Jacobson’s ruling. That sentiment was shared by several other experts reached by phone Thursday, all of whom said they needed more time to digest the lengthy opinion.

Any appeal would be in the spirit of a public policy fight that has dragged on longer than most people in New Jersey have been alive. The Supreme Court has repeatedly reaffirmed its commitment to a series of landmark housing rulings in the Mount Laurel cases that date to 1975, ruling for decades that the state’s poorest residents have a right to affordable-housing opportunities in their communities and that towns must allow a reasonable level of development.

But interpreting and enforcing the court’s housing decisions remain a persistent challenge.
It is 11:22am when the school alarm goes off, and for most students, it is seen as routine. They line up at the door and quietly file out of the classroom, knowing it is just another drill. But for some students on the autism spectrum, who might respond differently to the sound of the alarm or the unexpected disruption in routine, it is a sensory nightmare. They might move slowly, make noises, or have unusual behaviors. They might refuse to leave the classroom, or alternatively, might try to bolt out of the building to avoid the sound.

Lockdowns and evacuation drills are nothing new. Those of a certain age will recall Bert the Turtle, the animated star of the Civil Defense films of the 1950s. The “Duck and Cover” readiness training effort during the Cold War reassuringly reminded Americans fearing an atomic bomb: “If you see the flash, duck and cover.”

Safety drills can place unrealistic social, behavioral, and emotional demands on students with disabilities, but they need to be part of the drills in order to survive an emergency. So how can schools prepare to keep ALL students safe?

Most schools today have a comprehensive school safety plan, including lockdown plans for active shooters and other situations, but few have effective plans in place to address the complex needs of students with disabilities. There is no national model for such school-based crisis
preparedness. As a result, most schools are not fully prepared to support students with autism, sensory disabilities, medical and mobility disabilities, and other unique challenges in emergency situations.

In Marin County, in Northern California, educators have taken this issue on with a comprehensive plan they believe addresses the needs of ALL students by starting with the most vulnerable. The 36-page plan, developed in 2010, recognizes that there is no “one-size-fits-all” approach to planning, and takes a detailed approach to the planning process. For example, a child with a social or emotional disability may have a hard time understanding what is happening—they may not follow the rules and may resist direction. For these students, the plan recommends “regulated sensory input.” Also, a child with health-related disabilities may need to access medication or special equipment. A child with autism may need a lot of rehearsal with the drill itself.

“If you assure that you have planned for the most vulnerable in our school, then you have planned for everyone,” said Mary Jane Burke, the Marin County Superintendent of Schools and a former special education teacher. “That’s a good way to look at all of education.”

Many schools rely on an approach that forces students with disabilities simply to wait for help. Advocates at Wrightslaw, the online advocacy

---

Readers of a certain age may remember Bert the Turtle, the animated star of the Civil Defense films of the 1950s, who instructed children on how to prepare for a disaster during the Cold War.
Concerns about school safety are nothing new in America. However, schools must take new challenges and potential dangers into account when planning for safety in the twenty-first century.

They underscore that “sheltering in place and waiting for EMS to arrive” is not a comprehensive solution, not only because it leaves students in harm’s way but also because it can be terrifying.

Even with a school-wide plan, some parents and advocates suggest that students with complex disabilities have an individualized emergency plan. Such plans provide explicit instructions and support for each student during a school emergency. In general, a plan should ensure full integration, practice drills, staff training, and an evaluation process to identify obstacles before they arise.

According to Dr. Dusty Columbia Embury and Dr. Laura Clarke, both professors at Eastern Kentucky University, there are some core “drill skills” that all students need to be safe in a school crisis: they need to maintain silence, follow directions very quickly, maintain a position/location, manage feelings of stress/frustration without acting out, and manage changes to schedule. In a paper produced for Friendship Circle, they write, “Any one of these skills can be extremely problematic if not impossible for our children unless they are taught the necessary skills and provided with their required accommodations, including sensory supports, medical supports, and behavioral supports.”

They recommend that for some students, an Individual Lockdown Plan (ILP) should be part of the IEP process because it addresses potentially life-saving skills and supports the student’s needs. “[Educators] have to put something in place for the student to not just comply, but to acquire the skills to be safe and survive a crisis in school,” writes Embury.
Parents of children with disabilities should work with school personnel to incorporate an Individual Lockdown Plan (ILP) into their child’s IEP process to ensure safety in the event of an emergency.

One tool to teach these skills for students who require communication and behavior supports is a “social story” that includes pictures of appropriate school personnel and locations, and walks students through the expectations of any school crisis.

The research on “what works” in the area of school-based crisis planning and response is minimal, so there is little in the way of proven best practices. Most plans are based on what is known in other areas of crisis response. The literature on crisis management show four phases:

1. Mitigation and prevention, which address what school and staff can do to reduce or eliminate the risk;
2. Preparedness, which focuses on the planning for the worst-case scenario;
3. The response, which encompasses the steps to take in crisis;
4. The recovery, which deals with how to restore the learning and teaching environment after a crisis and get back to learning.

All school districts in New Jersey are required to have a school safety and security plan. Each plan must be designed locally with the help of law enforcement, emergency management, public health officials, and all other key stakeholders, and should be reviewed and updated every year. The plans and procedures must provide for:

1. The protection of the health, safety, security, and welfare of the school population;
2. The prevention of, intervention in, response to, and recovery from emergency and crisis situations;
3. The establishment and maintenance of a climate of civility;
4. Supportive services for staff, students, and their families.

Across the board, there has been little offered in the area of supporting students with disabilities. In 2015, the New Jersey School Security Task Force issued its report with a list of 42 practical recommendations to improve the safety and security of New Jersey’s school children, school staff, and school buildings. The report did not address the unique needs of students with disabilities in any way. The NJDOE’s 20-page list of minimum requirements for school safety and security, which was issued in 2011, does make mention of the need for schools to “establish procedures for assisting special needs populations, both students and staff,” but offers no further details.

Is Your School Ready?
In spite of the lack of clear direction and guidance in this area, school safety experts agree that schools must give special consideration to the unique needs of staff and students with
disabilities when developing the crisis plan. Procedures for evacuation and relocation will need to consider the student’s developmental, motor, communication, and sensory limitations. For example, a student who uses a wheelchair or walker may not be able to get down the steps of a building without help. Students with hearing disabilities may not be able to communicate verbally, to read lips, or to hear fire alarms or other emergency signals. Visual or reading disabilities might make it impossible for some students to read signs or cross an unfamiliar road or pathway. Even a fallen tree can obstruct the evacuation route and necessitate an alternative path or even an alternative shelter location.

But the risk is not over when the crisis ends. The response of law enforcement can be a matter of life and death, too.

In a compelling YouTube video, Holden Kasky and his father Jeff talk about the recent shooting at Marjory Stoneman Douglas High School in Parkland, Florida. Holden, who has autism, was barricaded in a classroom with his older brother

<table>
<thead>
<tr>
<th>School Emergency Evacuation Planning Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a roster of your students with special needs?</td>
</tr>
<tr>
<td>Have you identified students with special needs on site from other school districts?</td>
</tr>
<tr>
<td>Have you identified the medical needs of your students with special needs and their medication schedule?</td>
</tr>
<tr>
<td>Have you walked the evacuation paths and exits looking for potential obstacles?</td>
</tr>
<tr>
<td>Has an evacuation site been identified that is accessible to students and staff with special needs?</td>
</tr>
<tr>
<td>Is the primary evacuation path marked to clearly show the route?</td>
</tr>
<tr>
<td>Is there sufficient oxygen for 72 hours?</td>
</tr>
<tr>
<td>Have transportation needs been identified for the students with special needs, such as special vans and buses for students?</td>
</tr>
<tr>
<td>Do you have contract(s) in place with your transportation service provider(s) in case of an emergency?</td>
</tr>
<tr>
<td>Is there a master list of bus drivers?</td>
</tr>
<tr>
<td>Have you identified any necessary tools such as personal response plans, evacuation equipment, or visual aids for students with special needs?</td>
</tr>
<tr>
<td>Have you identified communication needs with students who have limited English proficiency?</td>
</tr>
<tr>
<td>Have you considered emergency accommodations for those with temporary disabilities?</td>
</tr>
<tr>
<td>Have you encouraged a relationship with students and the local responders?</td>
</tr>
<tr>
<td>Have you reviewed your plan with emergency responders?</td>
</tr>
<tr>
<td>Have you identified an evacuation site that is accessible to students and staff with special needs?</td>
</tr>
<tr>
<td>Have you identified a secondary evacuation site?</td>
</tr>
<tr>
<td>Have you identified all of your communication needs for your students with special needs?</td>
</tr>
<tr>
<td>Have you trained the staff on proper lifting techniques?</td>
</tr>
<tr>
<td>Have staff, students, and families been encouraged to provide 72 hour medications?</td>
</tr>
<tr>
<td>Has evacuation route information been compiled and distributed to staff?</td>
</tr>
</tbody>
</table>
and a group of other students with developmental disabilities when the shooting happened. Responding to questions from his father, Holden said, “I was very nervous ‘cause there was shouting, and they have a bunch of guns pointed in my face, with flashlights shining brightly in my face… (Police) were yelling ‘put your hands up, put your hands up.’”

“The students were freaking out and making lots of noises,” he said. “What are they going to do if they don’t put their hands up? Shoot em?” he asks.

Ironically, Jeff is a law enforcement volunteer and has worked to educate first responders on how to support and protect people with autism and other disabilities.

He believes that the training received by the Sheriff’s office in Broward County “paid off, in that there were no accidents.”

He urges other parents to make sure that local law enforcement has the training to recognize and respond to people with autism.

“It’s going to happen that they will encounter them,” he warns.

RESOURCES

Guidebook produced by the US Department of Education


The New Jersey Office of School Preparedness and Emergency Planning provides technical assistance about school safety, security, and preparedness.
609-588-2323.

New Jersey Center for School Safety
A network of communications and up-to-date training for New Jersey School Resource Officers, Probation Officers, School Administrators, and Educators.
http://www.njsafeandsecure.org/

Produced by the Council of Educational Facilities Planners International
http://media.cefpi.org/SafeSchoolsGuide.pdf


NJDOE School Safety and Security Plans: Minimum Requirements (2011)
http://www.state.nj.us/education/schools/security/req/req.pdf
Carole Johnson was sworn in as Commissioner of the NJ Dept. of Human Services on April 2, 2018.
For five and a half years, Carole Johnson was on the front lines of health care policy, serving in President Obama’s White House.

As a senior health policy advisor for the 44th president, Johnson worked to increase health insurance coverage for millions of Americans through the Affordable Care Act (ACA). She also had the critical task of improving services and choices for individuals with disabilities.

With a daunting agenda, Johnson was also assigned to help expand supports for older Americans, increase coverage of mental health and substance use disorder treatment, and improve health and economic security for all Americans.

With such diverse and robust experience, Gov. Phil Murphy tapped Johnson on January 3 to serve as acting commissioner of the state Department of Human Services (DHS), which oversees the state Division of Developmental Disabilities (DDD). It is a tremendous responsibility; the department serves about 2.1 million New Jerseyans each year with a $17 billion budget and a 7,000-member staff.

Johnson said her diverse experiences in Washington, D.C., working with various constituents, will be put to good use in New Jersey.

“It was a terrific opportunity to work in the White House; the President challenged us every day to better the lives of American citizens,” she said. “There was a lot of work to get the ACA implemented, while we also worked on other public health issues, such as Ebola, the Zika virus, lead water contamination, and drug shortages.”

Cecilia Muñoz, a senior staff member to President Obama for his entire eight-year tenure, served as Johnson’s boss.

As Assistant to the President and Director of the Domestic Policy Council, which coordinated the domestic policymaking process in the White House, Muñoz worked closely with Johnson on the day-to-day agenda.

“Carole Johnson is simply one of the most talented public servants I have ever worked with,” Muñoz said. “She is driven by the things you need most in order to deliver for people: data, compassion, commitment to results, and heart. The people of New Jersey are lucky to have her in their corner.”

Johnson, a North Cape May native who now lives in Hamilton, also has strong Capitol Hill experience. She interned for former U.S. Congressman Bill Hughes (D-2nd Dist.), who represented the Jersey Shore and Pine Barrens, as well as major South Jersey cities like Vineland and Atlantic City, for 20 years, through 1995.

Johnson also served the Senate Special Committee on Aging, the Senate Finance Committee, and the House of Representatives Ways and Means Committee. Moreover, she
managed health care workforce policy issues for the U.S. Department of Health and Human Services Health Resources and Services Administration.

Johnson previously was policy director for the Alliance of Community Health Plans, an association of nonprofit health plans; program officer with the Pew Charitable Trusts Health and Human Services Program; health policy researcher at the George Washington University; and, senior government relations manager with the American Heart Association. She earned her undergraduate degree from The Catholic University of America and her graduate degree in Government from the University of Virginia.

Gov. Phil Murphy, during the January 3 announcement, said he chose Johnson because she understands the importance of healthcare and other social safety-net programs and realizes the potential in all citizens, including those who seek help.

“And that job is getting tougher in the face of federal policies that could potentially put those already in the margins further from our grasp,” said Murphy, as quoted in NJ Spotlight. “On a national level,” he said, “New Jersey can no longer stand silent, but must help to lead the fight” to protect Medicaid and ensure continued support for programs like the Children’s Health Insurance Program (CHIP), which Congress has declined to fund this year for the first time.

“We need strong leadership that understands that even one person falling through a hole in the safety net is one too many,” the governor added.

Johnson said she was “humbled and honored” to return to her home state and run the DHS for Murphy.

“This department provides the supports and services for people with developmental disabili- ties to lead full lives,” Johnson said. “This depart- ment, and the people who work for it, is about
giving people with disabilities, as well as their families, opportunity. I was nominated to drive this mission.”

Johnson said she looks forward to using her skills in developing and negotiating legislation, as well as managing multi-million dollar grants. “Understanding this state, listening to stakeholders, building strong teams and working collaboratively with other lawmakers and partners are all really important to me,” the commissioner said.

Johnson said she is still getting acclimated to the position, but has been quick to identify two prevailing goals:

- Identify barriers, improving access to care and services.
- Ensuring DHS is “public facing” and as user-friendly as possible.

“There is an array of services under one roof at DHS,” Johnson said. “So we think holistically and meet people where they are, rather than program silos. We want to make sure New Jersey residents know what supports are available.”

That begins with ensuring an open dialogue between the state agency and the constituents it serves. Johnson said she has already met with many self-advocates and their families to learn their needs and concerns. She noted she has met with leadership of the New Jersey Council on Developmental Disabilities, a key stakeholder.

“I want to use that input to make positive change,” she said. “We need to reach out to service recipients and give them the tools to make informed choices about our programs and services, as well as system improvements that are happening. So this will be a real and full communication loop.”

The commissioner, who was less than three months into the position when she was interviewed for this profile (she was officially sworn by Governor Murphy on April 2), did not want to delve into specific policies and issues with People & Families, but there is one topic of concern she wanted to address: Potential cuts to Medicaid at the federal level.

Johnson said the expansion of Medicaid through the ACA ensured that 800,000 New Jerseyans would get health insurance, as well as health and economic security. But talks of Medicaid cuts in Washington, the “uncertainty in the churn, is unnecessarily disruptive to the people of New Jersey and our economy,” she said.

The commissioner noted how the unified voice of the disability community prevented proposed Medicaid cuts from being enacted last year in Washington. “I will build on the foundation of New Jersey being continually vigilant about the values and importance of Medicaid,” she said.

Murphy and Johnson said the state alone cannot support Medicaid, which depends on more than $4 billion in federal dollars each year, or the ACA expansion now under direct attack.

“There is no replacing the federal government’s commitment to resources for the Affordable Care Act,” Johnson said, urging federal representatives in Congress to work together to strengthen the program, not eliminate it. “I will say, we have to be prepared for all contingencies” here in New Jersey. P&F
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 living at home with their families. 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 or individuals 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.

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 a developmental disability.

The system of Family Support shall include, but not be limited to:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers
<table>
<thead>
<tr>
<th>Number</th>
<th>Location</th>
<th>RFSPC #</th>
<th>Address</th>
<th>E-mail</th>
<th>Chair/Co-Chairs</th>
<th>Meeting Times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sussex, Warren, Morris</td>
<td>#1</td>
<td>PO Box 12</td>
<td>Pompton Plains, NJ 07444</td>
<td>Margaret Hefferle</td>
<td>Pompton Plains Market Cafe 34 Sylvan Way Hanover, NJ 07054 7:00 p.m.—9:00 p.m.</td>
</tr>
<tr>
<td>2</td>
<td>Bergen, Hudson, Passaic</td>
<td>#2</td>
<td>PO Box 443</td>
<td>Jersey City, NJ 07302</td>
<td>Frank Fiore, Fel Lim</td>
<td>Secaucus Public Library 1379 Paterson Plank Rd. Secaucus, NJ 07094 6:30 p.m.—8:30 p.m.</td>
</tr>
<tr>
<td>3</td>
<td>Somerset, Union</td>
<td>#3</td>
<td>PO Box 5997</td>
<td>Hillsborough, NJ 08844</td>
<td>John Brewer</td>
<td>Arc of Somerset County 141 S. Main St. Manville, NJ 08835 7:00 p.m.—9:00 p.m.</td>
</tr>
<tr>
<td>4</td>
<td>Essex</td>
<td>#4</td>
<td>PO Box 1742</td>
<td>Bloomfield, NJ 07003</td>
<td>Rebekah Novemsky, Yolanda Smith</td>
<td>Bloomfield Civic Center Music Room 84 North Broad St. Bloomfield, NJ 07003 7:30 p.m.—9:30 p.m.</td>
</tr>
<tr>
<td>5</td>
<td>Hunterdon, Middlesex, Mercer</td>
<td>#5</td>
<td>PO Box 76</td>
<td>Lakewood, NJ 08701</td>
<td>Mike Brill</td>
<td>Lakewood Municipal Bldg. 231 Third St., 2nd floor Lakewood, NJ 08701 7:30 p.m.—9:30 p.m.</td>
</tr>
<tr>
<td>6</td>
<td>Monmouth, Ocean</td>
<td>#6</td>
<td>PO Box 76</td>
<td>Arc of Atlantic County 6550 Delilah Rd., Suite 101 Egg Harbor Twp., NJ 08234</td>
<td>Mary Ann Philippi</td>
<td>BTC 110 Kings Hwy North Kings, NJ 08034 Evening - 7:00 p.m. — 8:45 p.m. Bankcroft School; Activity Center 310 W 7th Ave Mt. Laurel, NJ 08054</td>
</tr>
<tr>
<td>7</td>
<td>Burlington, Camden</td>
<td>#7</td>
<td>PO Box 700</td>
<td>Trenton, NJ 08625</td>
<td>Laura Kelly, Kathy Freeman</td>
<td>Cherry Hill Public Library; Main Floor 1100 Kings Hwy North Cherry Hill, NJ 08034 Evening - 7:00 p.m. — 8:45 p.m. Bankcroft School; Activity Center 310 W 7th Ave Mt. Laurel, NJ 08054</td>
</tr>
<tr>
<td>8</td>
<td>Cumberland, Salem, Gloucester</td>
<td>#8</td>
<td>PO Box 700</td>
<td>Trenton, NJ 08625</td>
<td>Sandra Backenst, Lisa Parles</td>
<td>Monthly teleconferences will be held in Jan - June 2018 in lieu of face-to-face meetings. For call-in information, email Co-Chairs</td>
</tr>
<tr>
<td>9</td>
<td>Atlantic</td>
<td>#9</td>
<td>PO Box 700</td>
<td>Arc of Atlantic County 6550 Delilah Rd., Suite 101 Egg Harbor Twp., NJ 08234</td>
<td>Mary Ann Philippi</td>
<td>BTC 110 Kings Hwy North Kings, NJ 08034 Evening - 7:00 p.m. — 8:45 p.m. Bankcroft School; Activity Center 310 W 7th Ave Mt. Laurel, NJ 08054</td>
</tr>
<tr>
<td>10</td>
<td>Cape May</td>
<td>#10</td>
<td>PO Box 199</td>
<td>South Dennis, NJ 08245</td>
<td>Anne Borger</td>
<td>Cape May Special Services School 148 Crest Haven Dr. Cape May Court House, NJ 08223 Meeting times TBD</td>
</tr>
</tbody>
</table>
"I want them to know that I’m not afraid anymore.” —Todd Emmons
Abuse and Exploitation of People with Developmental Disabilities

By Brenda Considine

Trigger Warning: Sexual trauma, abuse, and pejorative language.

Authors note: Reading the unvarnished first person account of abuse is very difficult. In order to be honest, and for respect for the courage of the victims of these abuses, I have not removed language or edited these direct accounts. They are told here, as they were told to me.

Todd Emmons is resilient.

Todd lives in Voorhees, in a group home operated by Bancroft. He enjoys a rich life with his girlfriend, Lisa, good friends, and family. Born and raised in South Jersey, Todd knows a lot of people and keeps a busy schedule, including bocce ball in Special Olympics. A graduate of Project Take Charge and Partners in Policymaking, Todd has served as a member of the New Jersey Council on Developmental Disabilities for more than a decade and is an active speaker and advocate.

But there is a private story—decades old—that still lives inside of him. The sadness and anger bubble up as he tells it:

“It was at night. The staff would supervise us when we took a shower to make sure we were getting clean. There were stalls with showers in them—I was in my stall. One staff member was watching me and he walked closer and just stood too close to me. He undressed himself behind me and touched me on my chest and on my private area. I did not know what to do. I was scared to death.”

The abuse began when Todd was just 14, living at a Developmental Center in Southern New Jersey. Terrified to tell anyone about his ordeal, Todd would be raped five more times, his clothing torn from his body.

“It started as ‘name calling’ within a few months of the time I moved in. They would say, ‘Here comes retard-boy Todd. Here comes the retard.’”

“After that, there was more abuse. One woman who was supposed to be taking care of me took my arm and smacked it against a light pole. She just whacked it and whacked it and whacked it.”

In tears, and gesturing to his shoulder, forearm, wrist and hand, Todd continues his story:

“. . .and she broke my bones here, here, here and here. Then they told my mom that I did it to myself, but I didn’t.”

“I hated them. I hated all of them. Why did they do that to me? I was just a boy.”

“And they always told me that if I told my mom, or if I told anyone, they would hurt me more.”

“I am telling my story because I want people to know that this can happen to anyone. It is not just girls and women. It is boys and men, too.”

“And I also want them to know that I am not afraid anymore.”
Widespread and Underreported

Recently the #MeToo movement has brought awareness of sexual harassment, abuse, and exploitation to mainstream media. With that has come increased support to victims through advocacy and access to resources for healing. But exploitation and abuse can affect anyone. There is a group of victims whose stories have yet to be told: those with developmental disabilities.

According to data from the U.S. Department of Justice and reported on National Public Radio, people with intellectual disabilities are sexually assaulted at a rate that is seven times that of people without disabilities. DisabilityJustice.com, an online resource dedicated to protecting the rights of people with developmental disabilities, reported that people with disabilities are particularly vulnerable to sexual, workplace, and financial exploitation.

Most abuse goes unreported, either because it is never detected, or because of fear of retaliation. A 2014 U.S. Department of Justice report compiled data from 2009-2012, and found that the age-adjusted violent victimization rate for people with disabilities was more than double the rate among people without disabilities. They suggest that this is because people with disabilities are less likely to access the justice system or articulate the abuse or exploitation. And, if the disability is more severe, the victim may not even understand they are being abused. As in Todd’s case, the abused victim often knows and trusts their perpetrator: often a family member, acquaintance, or someone on whom they rely for assistance such as a residential staff member, personal care attendant, or transportation provider.

What Constitutes Abuse

Abuse can take many forms: sexual, physical, emotional, and neglect. How does one identify if a behavior is abusive? Abuse is defined as a clear violation of the victim’s sense of dignity often resulting in shock, fear, anxiety, traumatic stress disorder, and sometimes, physical pain. Abuse appears as unwanted sexual activity, violence, humiliation, verbal assault, and intimidation against the victim. A related threat to people with developmental disabilities is exploitation, or any unfair practices that take advantage of vulnerabilities, directly or through coercion. This can be in the form of paying individuals with disabilities far less than their coworkers, being misled by someone who removes funds from their accounts, or having personal items stolen or “traded” well below their value. Sometimes, people with disabilities are even coerced into being party to a crime.

Types of Emotional and Physical Abuse and Exploitation

- Exposure to domestic violence
- Insults and harassment
- Isolation
- Threats of violence
- Denial of sanitary living conditions
- Unnecessary or excessive physical handling
- Ignoring dietary restrictions
- Over-medication
- Bathing in water that is too hot or cold
- Inhumane employment environment
- Prostitution

Recognizing signs and symptoms of abuse or exploitation in people with developmental disabilities can be difficult, so it is important for caregivers to recognize physical, health, or behavior changes that are uncharacteristic of the person’s typical manner. Common symptoms of abuse, neglect, and exploitation include bruises, burns, sudden difficulty walking or sitting, dehydration, poor hygiene, sudden fear of being touched, changed sleep patterns, depression, mood swings, sudden problems paying bills, or unexplained disappearance of money or valuables.

For nearly three years, Emma Adoula suspected that her son, Abdulaye, was being abused.
in a group home in North Jersey. Abdulaye, who has autism, has very challenging behaviors, and does not use words to communicate, so Emma had to rely on his behavior, and the wounds she found on her son, as well as accounts from other residents of the group home:

“We noticed marks on his body that would not heal. No one knew what happened to him. We reported it and they promised to do body checks, but the situation did not get better.”

“They were using mechanical restraints on my son, but there were huge marks on his back that no one could explain, and deep cuts to his body.”

“On Sunday, staff from the group home brought Abdulaye to meet me at church. When they brought him to me, my heart fell to my feet. His shirt was bloody and there was a giant bandage on his chin.”

Emma and her family documented Abdulaye’s wounds with pictures and reported the apparent abuse to group home staff, leadership, and other authorities. There were many promises, but no answers. Some suggested that her son’s abuse may have come from his roommate, or other residents, but no one could say for sure. Over the course of several months, Abdulaye was taken to the emergency room for treatment of other unexplained injuries: a black eye; a broken nose; a chipped tooth. It was the hospital social worker who finally called the police; reporting it as a case of abuse and launching an investigation. But because Abdulaye has limited communication skills, it was nearly impossible for law enforcement or the state to substantiate abuse allegations, or determine who had done this to him.

“Aafter we reported this, group home staff intimidated us and threatened us. They told us not to talk about it.”

Over the next year, Abdulaye lost more than 35 pounds, and lived in two separate group homes operated by the same agency. Because of his complex needs, housing options were very limited. There were additional instances of unexplained bruising, a cut to his head and other troubling signs of possible abuse.

Once the family contacted Disability Rights New Jersey (DRNJ), they got the help they needed to move their son.

“They agreed with us and helped us follow up and take steps to keep him safe. Rebecca asked them a lot of questions—she seemed to know exactly what was happening and how to talk to them. They got him out of there.”

Rebecca Kasen, LSW, a staff advocate at DRNJ for the last three years, handled the case. She said Abdulaye’s abuse is one of the most serious substantiated cases they have had in a long time.
“We got all the state reports, and we held meetings with the providers. They were open with what had happened, but they disagreed with my assessment that there was a cultural problem in that group home. There was a lot going on there,” she said.

Eventually, DRNJ advocates pushed the state to find a new place for Abdulaye to live.

Jill Hoegel, LCSW, is the Coordinator of the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program at DRNJ. She said it is often very difficult to substantiate abuse, particularly when the individual is nonverbal or when they themselves have a history of self-injurious behavior. In a year, her program may handle fifty or more cases of abuse or neglect, but very few are substantiated.

“When the victims and witnesses are nonverbal, and the only verbal people are the staff, it is really hard. We don’t have the facts—we have only the evidence of the physical abuse. There is no real proof of how it happened or who did it.”

“This is why it is vital that caregivers call us and call the police when they see unexplained injuries. We often find patterns when things are reported to us. By the time we get a report, it is often not the first time it has happened,” she added.

Abdulaye is now at another agency and doing well, but he and his family have a very hard time trusting caregivers after everything they have gone through.

**Prevention**

Abuse, neglect, and exploitation are harmful, damaging, and illegal. While understanding the signs and symptoms will help determine if abuse or neglect might be present—setting up barriers to prevent the likelihood of any occurrence from happening at all is invaluable in protecting a vulnerable person with disabilities from danger and harm. Preventative measures you can take include: conducting background screenings and reference checks of prospective caregivers before they start working on an unsupervised basis; unannounced visits at different times of the day; expanded social circles so there are less periods of isolation; and most importantly, educating direct care staff to understand exactly what constitutes abuse, neglect, or exploitation and the consequences they will face should any misconduct occur.

Emma Adoula’s advice for other family members:

1. Be very very vigilant—you are the one who knows your loved-one with disabilities best.
2. Monitor your loved-one’s program. Drop in and check in, unannounced.
3. Watch for the signs—they are there, even if staff do not tell the whole story.
4. Know that you can move your loved-one if you are not satisfied.

Having a system in place to prevent abuse is a tremendous leap in helping people with disabilities. However, one of the most crucial and effective ways to protect people with mild and moderate developmental disabilities is to provide them with information about abuse and teach them strategies so they can protect and empower themselves. **ESCAPE-NOW**, a curriculum designed for abuse prevention by Columbia
University, identifies some evidence-based strategies as: teaching individuals with developmental disabilities to recognize an unhealthy relationship; helping them create immediate and long-term ‘personal safety’ as a goal; helping them learn assertiveness and communication skills; helping them develop skills for coping with the emotions associated with abuse and how to get help if needed.

Recovery
Todd has found recovery through support.

“For me, it was telling my girlfriend Lisa what happened to me. She cried with me.”

“Now, I am happier than I’ve ever been, but there are days when I am still angry.”

“I am working hard on that. I just know it was not my fault.”

Tracy Higgins, MA, LPC and Melissa Keyes DiGioia, CSE are co-founders of Finding Your Individuality, a New Jersey-based organization that educates all people with a focus on abuse prevention of people with disabilities. They use an approach called “Trauma Focused Care” to help guide people through the recovery process. Trauma Focused Care is designed to help victims rebuild a sense of control and empowerment.

RESOURCES
If you have reasonable cause to suspect that a person with disabilities is being abused, neglected, or exploited, or even neglecting themselves, you can:

1) Call 911.
2) Call NJ Division of Developmental Disabilities at 800-832-9173.
3) Go to the hospital emergency room.

Finding Your Individuality.com, 775 Mountain Blvd., Watchung, NJ 07609 – 908-552-4469

RAINN (Rape, Abuse & Incest National Network) 24/7 hotline 800-656-4673 or an online chat at http://online.rainn.org,

NJCASA (The NJ Coalition Against Sexual Assault) https://njcasa.org/find-help/

ESCAPE-NOW, a curriculum designed for abuse prevention by Columbia University, escapenow.wikischolars.columbia.edu
When Hollis Painting, communications director at Advancing Opportunities in Ewing, contacted me about Carly Hewitt, she told me that the 23-year-old had a compelling story to tell. Hewitt reached out to me by email soon after, expressing an interest in being interviewed. I didn’t realize as I tried to set up a phone interview with Hewitt that she is mostly nonverbal. We began our communication by email, and I soon learned that Hewitt was emailing me using only her eyes. We set up an appointment to meet in person.

In the meantime, I spoke with Jeannette Van Houten, an assistive technology consultant at Advancing Opportunities, who has been assisting Hewitt in gaining self-sufficiency through the use of hands-free computer access. Hewitt was in the process of transitioning from high school to college when she began working with Van Houten. She had been using an old computer system that wasn’t right for her.

Hewitt explained that her disability affects all of her muscles. “I am on a ventilator 24/7 and in a wheelchair. I had a computer where I activated a switch on my forehead. This was very tedious because when I had to write anything, I had to wait for the scanner to scan each letter that I wanted to type. This would literally take hours to type a small paragraph.”

The State Division of Vocational Rehabilitation (DVRS) referred Hewitt to

Although she has Spinal Muscular Atrophy, a developmental disability that affects all of her muscles, Carly Hewitt is able to have a greater level of independence and self-sufficiency with the help of assistive technology.
Advancing Opportunities to address her needs. She met Van Houten, who wanted to make independence achievable for her. Van Houten knew that Hewitt wanted to do everything young women her age did, such as attending college, working, shopping, emailing, and using social media. But the older computer system she was using wasn’t reliable. The single copper switch strapped to her forehead only operated when her eyebrow would twitch, and it required constant repositioning. Since the switch required conductivity to her skin, it wouldn’t work with perspiration or dry skin. “She had to be wired to the computer every time she wanted to type something, and there were a lot of wires. It was a failure and a lot of frustration. Carly would get tired and only have enough energy to do so much,” said Van Houten.

She considered Hewitt’s college needs, as well as her future employment needs. “We knew it would be extremely frustrating in college and in the job world to spell each word letter-by-letter and to hope her switch worked on a regular basis. We needed something better that would work consistently.”

Through Advancing Opportunities’ Technology Lending Center, Hewitt tried three eye-gaze systems to find the right one and chose the Tobii Dynavox eye tracker. This allows her to have complete access to her computer. “There is nothing on her computer that she cannot use. It’s quick, which is important. She can do the things she wants to do—writing papers, researching, emailing, social media—all the things you and I do on a daily basis. I told her to only spend 15 minutes at a time using the system, but she wouldn’t stop using it. She can spend two-to-three hours on the computer without having problems. She has a freedom that she didn’t have otherwise.”

At her Sayreville home, Hewitt, now 23, demonstrated to People & Families photographer, Rebecca Shavulsky, and I how she uses her laptop system. Her mother, Lori Hewitt, and her nurse, Cathy Marinaro, set up her laptop and a small camera that is about the size and shape of a pen on the dining room table. Hewitt’s eyes are calibrated to the camera, called the PC Eye Mini. When she settles her gaze on a letter, the laptop types that letter. When she settles her eyes on a left-click mouse icon, it performs a left-click. Using only her eyes, Hewitt left clicked her mouse, opened her word processing software and began typing. She then quickly showed me how she could switch from word processing to Twitter and Instagram, where she scrolled through all the pictures she has posted.

After graduating with honors from Middlesex County College, she now maintains an A average at Rutgers University New Brunswick, where she is being inducted into the psychology honor society. She majors in psychology and minors in education. Her mother, Lori Hewitt, said, “Carly’s education is very important to her. She is very determined to succeed in everything. She doesn’t give up.”

Carly Hewitt said, “I always wanted to become an elementary school teacher, but with my physical limitations, I realized that this would be a tough career to have, so I decided that I want to do something with psychology and children. I am so blessed to have the opportunity to go to school and be able to use assistive technology to help me with everyday tasks that everyone else can do independently.”

Hewitt’s life has its share of difficulties, so it’s important that her computing is as easy as possible to do. Her medical care is time consuming, requiring 16 hours of daily nursing care. Her
mother handles the other eight hours daily. She needs suctioning of her tracheostomy tube, respiratory treatments with a nebulizer, tube feeding, and someone to manage all her daily living needs.

Her mother is pleased with the services provided by the Disability Services Office at Rutgers New Brunswick. “Carly likes Rutgers even more than the county college. They are great at accommodating her. They put her notes online so she doesn’t need a note taker in class. A proctor takes tests with her. She takes essay tests on her computer.” Marinaro or her other nurse, Lisa Springer, accompany her to school and do things such as helping her respond to multiple choice test questions. Her nurses have been with her most of her life and they are fluent in using the Tobii Dynavox.

Like most people her age, Hewitt also enjoys recreational activities. She attends country music concerts and Rutgers basketball games, hangs out with her cousins, goes shopping, goes to the movies, and goes roller skating with her mother or sister Megan, 26, pushing her wheelchair around the rink.

Van Houten points out that Hewitt’s life is richer from using her computer system. “Using the computer gives Carly a chance to have ‘me time.’ Carly can listen to music, go on social media, and do whatever she wants to do. It’s not always about work or school. Her mom can do something else. They might be in the same room, but they are doing separate things. It’s been good for the whole family.”

Van Houten is continually impressed by Hewitt’s never-give-up spirit. “She doesn’t know what ‘no’ means. To her, it just means she has to try harder, work harder, change someone’s mind. She doesn’t accept ‘no.’ Nothing will stop her from following her dream. She chases that dream and makes it work.”

Hewitt can’t say enough about how her eye-gaze system helps to make that possible. As I sat next to her at her home, she brought up a Word document and typed, “This computer is my life-line because I can do what everyone else can do. I don’t know where I’d be without it.”

RESOURCES

Advancing Opportunities’ Technology Lending Center is free for people with disabilities, their families and the organizations who work with them in New Jersey.

For more information, call 1-888-322-1918, extension 536, or go to: https://www.assistivetechnologycenter.org/technology-lending-center

PC Eye Mini

Tobii Dynavox Products
New Jersey has joined the ranks of nearly every other state in the nation to regulate the use highly restrictive behavioral teaching techniques on children and teens with disabilities. In one of his final acts as Governor, Chris Christie signed legislation regulating the use of seclusion techniques and physical restraint procedures with students with disabilities. The law P.L. 2017, c 291 takes effect immediately.

The new law does two things:
1. It establishes certain requirements for the use of restraint and seclusion on students with disabilities AND
2. It requires the New Jersey Dept. of Education (NJDOE) to establish guidelines for schools to ensure a review process is in place to examine the use of physical restraint or seclusion. That review process shall include educational, clinical, and administrative staff.

Community Perspective
The disability community could not be more divided around this bill, with Autism New Jersey and The Arc of New Jersey in favor of the bill, and child advocacy organizations, including Statewide Parent Advocacy Network (SPAN) in strong opposition, but this issues and challenges are nuanced.

Autism New Jersey sees the new law as directly benefitting students with disabilities and their teachers by providing clear guidance on when restraint and seclusion should be and should not be used, how they should be monitored and documented, and how those who are responsible for implementation are to be trained.

“Prior to this bill, there was no state policy that regulated the use of restraint and seclusion for students with disabilities in public or private schools. This bill provides the guidance needed to ensure that schools that are using restraint..."
and seclusion are doing so in a manner that is safe, warranted, transparent, and accountable,” said Dr. Suzanne Buchanan, Autism New Jersey Executive Director.

But child advocates see the new law through a different lens.

“Some will say this new law is better than nothing. I could not disagree more,” said Renay Zamloot, a non-attorney child advocate. “It is my unwavering belief that every student should be educated with dignity within a safe and positive learning environment. Restraint should be viewed as an option of last resort to be used in cases of emergency only. It should not be elevated, via regulation, to a legally acceptable practice.”

Data*  
- One out of 100 special education students was restrained in 2014 by school personnel.
- Nearly 70,000 students experienced restraint in 2014, most on more than one occasion.
- Data are dramatically understated, as many states, including NJ, do not report data.
- Students with disabilities account for 12% of the nation’s school children, but account for 67% of those subject to seclusion and restraint.

(*) Data are based on annual of Education Week Research Center of data collected by the USDOE Office for Civil Rights.

**Office of Civil Rights**
In December 2016, the US Department of Education (USDOE) Office of Civil Rights issued a “Dear Colleague” letter to inform school districts how the use of restraint and seclusion may result in discrimination against students with disabilities in violation of Federal laws that prohibit disability discrimination, including Section 504 of the Rehabilitation Act of 1973 (Section 504)

**From the paper:**
A school’s use of restraint or seclusion may have a traumatic impact on a student, such that even if she were never again restrained or secluded, she might nevertheless have new academic or behavioral difficulties that, if not addressed promptly, could constitute a denial of a Free and Appropriate Public Education (FAPE). That traumatizing effect could manifest itself in new behaviors, impaired concentration or attention in class, or increased absences, any of which could, if sufficiently severe and unaddressed, result in a denial of FAPE for that student. The repeated use of restraint or seclusion in school could deny a student’s receipt of FAPE in another way. Consider a student with a disability who engages in behavior in response to which the school secludes him for extended periods and on multiple occasions. While secluded, the student does not receive educational instruction or services. Cumulatively, the school’s repeated use of seclusion with that student could result in the school’s failure to comply with the Section 504 team’s decision about the regular or special education, related aids and services, or supplemental services and modifications that the student needs, or the appropriate setting in which to receive those services, and therefore may constitute a denial of FAPE.

**In Practice**
Zamloot, who provides direct advocacy assistance to families with children in special education, has been personally involved in more than 100 cases of restraint and seclusion, most involving young children, ages 3-10.

“In every case, the restraint/seclusion occurred as a result of the failure on the part of the student’s school district to conduct the legally required evaluations and develop an appropriate program. In nearly every case, the abusive practices of restraint and seclusion led to diagnoses of Post-Traumatic Stress Disorder and physical injury,” she added.

Autism New Jersey takes a very practical approach. According to their website, the day-to-day reality in many schools is that some students with disabilities do engage in severe challenging behavior which can put themselves and others in imminent danger. There are effective methods and techniques to decrease or
What the New Bill Requires

**PHYSICAL RESTRAINT:**
“Physical restraint” is defined in the bill as “the use of a personal restriction that immobilizes or reduces the ability of the student to move all or a portion of his or her body.”

1) **Emergency Only:** Restraint may be used ONLY in an emergency when student exhibits behavior that places them or others in immediate physical danger.

2) **Prone Restraint May Not Be Used:** A student may NOT be restrained in the prone position, UNLESS the student’s primary care physician authorizes the technique in writing.

3) **Training:** Staff involved in restraint must receive training in safe techniques for physical restraint AND the training must be updated at least annually. The training must be provided by an entity determined by the board of education to be qualified to provide the training.

4) **Visual Monitoring:** Each incident must be carefully and continuously visually monitored to be sure it was used according to the established procedures set forth in a board policy developed in conjunction with the entity that trains staff in safe techniques for restraint in order to protect the safety of the child and others.

5) **Written Documentation:** Each incident must be documented in writing in sufficient detail to enable staff to develop or improve the student’s behavior intervention plan (BIP) at next IEP meeting.

6) **Minimize the Use:** Schools must attempt to minimize the use of physical restraints through the inclusion of positive behavior supports in the student’s BIP.

7) **Parental Notification:** The parent or guardian must be IMMEDIATELY notified when restraint is used (phone or e-mail). A full written report of the incident must be provided to parent/guardian within 48 hours of the incident.

8) **Board Policy:** The bill references the need to ensure that procedures are used “in accordance with established procedures set forth in a board policy developed in conjunction with the entity that trains staff in safe techniques for physical restraint in order to protect the safety of the child and others.”

**SECLUSION:**
“Seclusion” is defined in the bill as “the involuntary confinement of a student alone in a room or area from which the student is physically prevented from leaving, but does not include a timeout.”

“Timeout” is defined in the bill as “a behavior management technique that involves the monitored separation of a student in a non-locked setting, and is implemented for the purpose of calming.” Timeout procedures are NOT regulated in any way under this bill.

1) **Emergency Only:** Seclusion may be used ONLY in an emergency when student exhibits behavior that places them or others in immediate physical danger.

2) **Training:** Staff involved in seclusion must receive training in safe techniques AND the training must be updated at least annually. The training must be provided by an entity determined by the board of education to be qualified to provide the training.

3) **Visual Monitoring:** Each incident must be carefully and continuously visually monitored to ensure it is carried out in accordance with established procedures set forth in a board policy developed in conjunction with the entity that trains staff in safe techniques for restraint in order to protect the safety of the child and others.

4) **Written Documentation:** Each incident must be documented in writing in sufficient detail to enable the staff to use information to develop or improve the student’s BIP at next IEP meeting.

5) **Minimize the Use:** Schools shall attempt to minimize the use of seclusion techniques through inclusion of positive behavior supports in the student’s behavior intervention plans.

**NEW ROLE FOR NEW JERSEY DEPARTMENT OF EDUCATION**
NJDOE will establish guidelines for school districts, educational services commissions, and APSSDs to ensure that a review process is in place to examine the use of procedures. This review process might inform the student’s IEP, the student’s BIP, the classroom supports, or a staff member’s professional development plan.

Full text of the new law can be found here: http://www.njleg.state.nj.us/2016/Bills/S1500/1163_R2.PDF
prevent severe challenging behavior (e.g., Applied Behavior Analysis, Positive Behavior Supports, de-escalation techniques), but when situations arise in which these methods and techniques are not effective, the judicious—and regulated—use of restraint and seclusion can aid in ensuring the safety of everyone involved.

“This law will provide the necessary and overdue regulations and standards that schools need to keep everyone safe in emergent situations. With the proper monitoring, documentation, and analysis of data required under this law, we can examine the use of restraint and seclusion and work towards their reduction and elimination,” concluded Buchanan.

**New State Fiscal Rules Add to the Problem**

Ironically, while the Legislature was regulating the use of restrictive behavior modification techniques, the NJDOE was approving new fiscal rules that make it harder for state-approved private schools to use positive behavior supports.

According to Gerard Thiers, Executive Director of ASAH, a statewide non profit agency representing roughly 150 of New Jersey’s state-approved private special education schools, NJDOE new fiscal rules and practices, which took affect last June, disallow certain costs related to student reinforcements—rewards provided for positive behavior.

“Our schools serve some of New Jersey’s most complex and hard-to-serve students, many of whom are placed with us because of challenging behavior,” said Thiers.

According to ASAH, NJDOE fiscal rules put in place last June make it harder for private special education schools to use food to reinforce students, and also make it harder for them to customize reinforces by limiting what schools can purchase as student rewards—even disallowing some of the very things that some students will work for.

“We know what best practice looks like—positive supports – but the new rules are limiting our options,” he added.

In addition, according to Thiers, the NJDOE has also now determined that costs related to behavior modification are no longer “instructional” in nature, making it much harder for some private schools to balance their budgets in a child-centered way.

**Advocates Are Frustrated.**

“Rather than focusing on positive behavior supports and interventions, we have placed our most vulnerable students in harm’s way while greatly restricting parental rights in the process,” concluded Zamloot.

For its part, the New Jersey Council on Developmental Disabilities has re-energized its efforts around education and other children’s issues with a new subcommittee tasked with reviewing issues related to children under 21 and their families. Chaired by Council member Peg Kinsell, one of the first issues the committee will take up is that of seclusion and restraint.

“I firmly believe that New Jersey needs to ban these procedures. If a parent did these things, you would call the police,” said Kinsell.

“Schools should be safe. Period. How is it ever OK to pin a 5-year-old to the floor, or put a student with autism in a closed padded room? That has to end.”

**RESOURCES**

**USDOE Guidance Document on Seclusion and Restraint (2012)**

**Office of Civil Rights Fact Sheet (2016)**
https://www2.ed.gov/about/offices/list/ocr/docs/dcl-factsheet-201612-504-restraint-seclusion-ps.pdf
People 1st New Jersey

Advocacy By & For People with Disabilities

The international disability advocacy movement has come to New Jersey, fighting for civil rights and equality in our state.

Calling All Advocates

For People First New Jersey to grow and thrive, we’re calling on advocates from all over New Jersey to join!

- Make Positive Changes in the Community
- Speak Your Mind
- Take Action
- All People with Disabilities Welcome

Want to Make a Difference?

Visit www.njcdd.org or call 609-292-3745 to find out how to join or start a People First New Jersey chapter in your area.
Carole Johnson and self advocate Jim Corbett at a Developmental Disability Advocacy Network event in March, 2018.