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FDA Approves Device To Help Identify Autism Earlier

Reprinted from June 17, 2022 DisAbility Scoop by Michelle Diamant

The Food and Drug Administration said this month that it granted 510(k) clearance to EarliTec Diagnostics for its EarliPoint System, a prescription device that is “intended to aid in the diagnosis of autism spectrum disorder.” The move allows the tool to be marketed and used in children ages 16 to 30 months.

The device, which the company is calling the EarliPoint Evaluation for ASD, uses eye-tracking technology to analyze visual behavior that is imperceptible to the human eye and assess focus and responsiveness while a child watches a series of short videos showing social interactions between kids. Data is then cross-referenced with age-expected metrics to determine if a child is missing out on significant social learning.

In addition to helping clinicians determine whether children have autism, EarliTec said that its system includes the EarliPoint Severity Indices which provides information about a child’s level of social disability as well as verbal and nonverbal ability.

“This is a significant milestone as we continue to develop innovative technologies designed to improve the lives of children and families affected by autism,” said Sreeni Narayanan, chief technology officer of EarliTec in a statement. “How we quantify moment-by-moment behavior of a child not only provides objective measures of each child’s strengths and weaknesses today — measures that can be universally available and accessible to all families — it provides a digital health platform that can support care in the future, so that all individuals affected by autism receive timely, individualized care.”

The FDA approval comes a year after the agency granted its first authorization of a device to aid in the diagnosis of autism. That product known as the Cognoa ASD Diagnosis Aid and branded as Canvas Dx uses an algorithm to analyze information submitted by parents and health care providers and videos of the child in order to return a “positive for ASD” or “negative for ASD” response.

The Cognoa aid is approved for use in children ages 18 months to 5 years. The addition of the EarliPoint device — which the FDA determined is “substantially equivalent” to the one from Cognoa — gives clinicians a tool they can use with younger children, starting at 16 months. “Sometimes differences in development are so subtle that parents and pediatricians are hesitant to act until delays become more problematic,” said Dr. Christopher J. Smith, chief science officer at the Southwest Autism Research and Resource Center in Phoenix, one of the sites where research on the EarliPoint device was conducted. “EarliPoint represents a breakthrough that utilizes solid empirical data to facilitate earlier diagnosis of ASD. It literally gives years back to families that are better spent on intervention rather than waiting.”

EarliPoint was developed by researchers at Children’s Healthcare of Atlanta, Emory University School of Medicine and Yale University. The FDA based its clearance of the EarliPoint device on results from two studies, collectively involving 550 children.

Family Reunited Weeks After Son With ASD Kicked Off Flight

Reprinted from NJ.com/TNS | June 14, 2022 by Karim Shamsi-Basha

NEWARK, N.J. — When Carlos Pacheco, Jamie Greene and their three children visited Aruba last month, they expected a typical family vacation — nothing like the nightmare that caused two members to be stranded in the Caribbean for nearly a month.

On May 17, as the family was attempting to board their return flight from Aruba to Newark, their 15-year-old son Elijah, who has autism, experienced a sensory episode.

“We had gone on many vacations driving, and Elijah had never had any issues,” Pacheco told NJ Advance Media. “We flew to Disney last year, and he enjoyed the plane ride and even the roller coasters there. Nothing seemed to startle him, so we felt it was safe to go to Aruba.”

When the family began to board the United Airlines plane, Elijah stopped at the doorway and began to scream “toilet,” his way of saying something was wrong.

“I gave him gentle nudge and we made it to our seats, then he lost control. He refused to sit, and Jamie and I had to hold him down. Something caused him to be overwhelmed, and he began to hit (Greene) and me and continued screaming,” Pacheco said.

A flight attendant informed the parents that the captain had requested them to return to the gate. Elijah’s doctors in the United States had prescribed fast-acting medication in case the teen became agitated. The parents administered the medicine but there was no change in his behavior. They knew flying on a commercial airline was no longer an option, sensing it would trigger another episode.

Pacheco and Greene then tried a medical evacuation company but were turned down. A cruise line refused to help, too.

The family was stuck on an island, 2,000 miles from home.

“Even the U.S. Consulate in Aruba ran out of ideas, and I had to get our two other children back to school at Toms River, so Brandon, Brice, and I flew back,” Pacheco said.

As Pacheco recounted the ordeal last week, he watched a white van pull up outside his townhome.

“I think they’re home,” he said, jumping up and rushing outside to greet his wife and son, who in that moment had finally returned. They’d been gone since May 10.

Pacheco, Greene and Elijah embraced before Elijah ran inside to find his iPad.

“I cannot believe we’re finally home,” Greene said with relief. “At one point, I thought we would be stuck on Aruba forever.”

How they got home

On May 22, Julian Maha was scrolling through Facebook at his Birmingham, Ala. home when he came across Greene’s post pleading for help. Maha asked his friend Vicky Rey, vice president of guest care and communications at Carnival Cruise line, if she could assist. Rey arranged for one of their ships to divert course to Aruba and pick up Greene and Elijah, dropping them off in Miami.

Maha also asked two volunteers from KultureCity — a nonprofit organization Maha founded to promote sensory inclusion and acceptance for those with invisible disabilities — to drive from Atlanta to Miami, and then drive Greene and Elijah back to their home in Toms River.

“Given Carnival’s close partnership with KultureCity, our team has a deep understanding of the needs of individuals with sensory and invisible disabilities,” Rey said. “When the organization contacted us about Elijah’s situation and we realized we could bring him back to the United States on one of our ships, we did not hesitate to offer help.”

Maha adds: "I knew the minute I read that post that I had to help. I am grateful that (Greene) and Elijah are home safely. Their story resonated on so many levels since my autistic child Abram is of the same age as Elijah. My wife Michele and I identified with their sense of hopelessness and desperation."

On the board of KultureCity are several celebrities including "Jersey Shore" TV star Jenni Farley, aka "JWoww."

"The troubles that (Greene) and Elijah endured were truly heart-breaking," Farley said in a statement. "A few years back, my son Greyson became overstimulated at an airport and had a sensory overload experience. After I heard about (Greene) and her son, I reached out to her while she was stuck in Aruba. The situation is unfortunately all too common."

Greene appreciated the call from Farley.

"(Farley) was very supportive and told me that I was doing a great job through a very tough situation," Greene said. "I needed to hear that at the time. It meant a lot."

A new mission

A few minutes after the family was reunited, Greene looked at Pacheco next to her, then at Elijah playing with his iPad, and shook her head.

"Policies have to change. I understand that airlines must follow safety protocols, but something like this should have never happened," Greene said, noting how she wished the airline could have presented an alternate plan to return her and her child home and not left them to fend for themselves.

"Airlines should treat invisible disabilities the same way they treat visible disabilities. Invisible disabilities include autism, PTSD, traumatic brain injury, anxiety, ADHD, strokes and other mental health challenges," Greene added.

United Airlines policy on disability lists several types of special needs accommodations including wheelchair access, CPAP machines, and service animals, but does not list a specific policy for passengers with autism.

Greene wiped her eyes and continued: "We never thought this could happen to us. We now plan to be involved with KultureCity and the autism community. I'm seeing the silver lining, just the chance that a policy might change as a result of our story is enough for me."

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For more information or to donate , see information below:



Make the nevers possible by creating sensory accessibility and inclusion for those with invisible disabilities

kulturecity.org 732 Montgomery Hwy PMB 392 Birmingham, AL 35216 (205) 907-5659

KultureCity / Carnival Partnership -All Carnival ships including Carnival ships sailing from Australia are now Sensory Inclusive™ Certified with KultureCity's continuous training, sensory bags and app integration.

From Norman's Desk

Our nation celebrates its Declaration of Independence from Great Britain on July 4th. We celebrate the idea that this nation wanted to be free from rules, regulations, and laws created without input from the Colonies.

We need to remember what we are celebrating and why. We need to remember the sacrifices of those who have died for the concepts of independence, liberty, and freedom. We must also remember that the fight is not over for many people with disabilities and, indeed, for many who look, speak, worship, or feel different from what is deemed acceptable.

The promise has been slow in coming for people with disabilities, and for most of us, equality is still not here, is still a concept enjoyed by many others, and is a promise that still needs to be kept.

The promise is a lofty one, yet for some people with disabilities, the promise translates into more practical considerations: the freedom to make choices in their daily lives, to be responsible for their lives, and to be a contributing part of their community.

Freedom and independence are grand-sounding words, but they are empty and hollow words when government pandemic policies made the lives of people with disabilities expendable through improper planning or mere indifference to our fates.

Conversely, expecting the promise of freedom to be kept without struggle and sacrifice is foolhardy. Again, our history teaches that participatory governance over oneself or one's country means stepping up to participate and sacrifice. Elections have consequences, and the loss of rights is one of them.

Individuals must take up the cause of freedom, work together, and battle for the promise to be kept. This is imperatively truer now for people with disabilities than ever.

So, while we celebrate what happened 246 years ago, let us remember for many of us with disabilities the struggle for freedom continues!



Hurricane Season Has Individuals With Disabilities On Edge

By Emily Woodruff, reprinted from *The Times-Picayune* | *The New Orleans Advocate/TNS* | June 21, 2022

[Editor's Note: Some may find this story upsetting, but we present this as an example of why people with disabilities need to plan for themselves, have Plan B and C, and expect to fend for themselves for 72 hours.]

NEW ORLEANS — Every summer, Sue Bordelon starts to worry.

Her son Clarke, 28, has autism and a chromosomal disorder that makes him medically fragile. When hurricanes come, it's hard to go without power. But the horror of evacuating for Katrina taught them it's even more difficult to leave.

After Hurricane Ida struck their Algiers home last year, they lost \$1,600 of bone marrow medication when the electricity went out for two weeks. Day after day, Bordelon and her sister took turns fanning Clarke to keep him cool and encouraging him to read as a distraction. As she sat in sweltering temperatures, keeping a close eye on a manual feeding tube, Bordelon felt a familiar sense of despair.

"I told my sister, the next hurricane, I wish it would come right this way, completely take us out," she said, breaking into tears. "Then we wouldn't have to figure out what to do."

.After Ida, the city encouraged seniors and desperate families to call 311 and sign up for its special needs registry, but little was done in the days following the storm. Seven seniors died in their apartment homes before the city evacuated the buildings. Since then, the city has worked on dismantling the special needs registry and replacing it with another system called Smart911.

The special needs registry was started in 2013. Over the next few years, the city went door-to-door in low-income apartments to find vulnerable people. Officials also used Medicare data to pinpoint how many people might need help powering life-sustaining medical devices. Advocates welcome some of the changes, but worry Smart911 may have the same issues as the registry, said Nicole Williams, the education advocate for Families Helping Families NOLA. Williams, who has spina bifida, is on the registry herself.

"When I first signed up for special needs registry, I was under impression when a hurricane situation happened, someone from the city would start calling families," said Williams. "Those phone calls never happened. Will that same thing happen switching over?"

But what started with good intentions has become unmanageable. The list grew from 750 to 4,800 people by the time Ida rolled through, according to Meredith McInturff, the city's public health emergency coordinator.

"It kind of became this tool that was being promoted by all city leadership as, if you need any sort of assistance during a hurricane, you should get signed up for it," she said in a presentation to advocates. But the system didn't have the organization or workforce to follow through on that. It set up an "unrealistic expectation," said McInturff, "that every single person signed up would be evacuated out during a storm."

The City Council also passed a new ordinance for low-income senior apartment homes that requires that property owners communicate with the city about their emergency plans and whether they have back-up generators to power elevators on site. That way, Avegno said, the city has eyes on who needs help. But it does not require that the building owners have generators.

Charlie Nero, 36, signed up for the special needs registry because her daughter has cerebral palsy and relies on several medical devices. But when she got the offer to evacuate with Chloe, 6, before Ida, she was told she could only bring one bag. Her 13-year-old daughter wouldn't be allowed on the bus. The equipment Chloe requires to live — multiple chairs, suction devices, bottles of milk, diapers, feeding tubes and a pump — would take up an entire van. The only way she can transport Chloe, who uses a trach to breathe, is by holding her in the backseat.

Despite A First-Ever ‘Right-To-Repair’ Law, There’s No Easy Fix For Wheelchair Users

By Markian Hawryluk, reprinted from Kaiser Health News | June 17, 2022

Robin Bolduc isn’t the type of person who takes “no” for an answer — particularly when it comes to fixing her husband’s wheelchair.

Her husband, Bruce Goguen, 69, is paralyzed from multiple sclerosis. And without his chair, he would be stuck in bed, at risk of developing pneumonia or pressure sores that could lead to sepsis and death.

When components of the chair wear out or break down, the road to repair is littered with obstacles. Recently, the Broomfield, Colo., residents had to replace a button that Goguen presses with his head to control his wheelchair. They considered going through his wheelchair supplier for the repairs. “If we did that, he would literally be in bed for months,” said Bolduc, who, along with her husband, is a member of the Colorado Cross-Disability Coalition, an advocacy group. “There’s a quality-of-life issue — he could be lying in bed staring at the ceiling. He has no movement without his wheelchair.”

But, instead, Bolduc tracked down the manufacturer, ordered several buttons online for \$20 each, and discovered that replacing the part herself was simple. “It’s a plug,” she explained. “It’s like charging your cellphone.”

The multibillion-dollar power-wheelchair market is dominated by two national suppliers, Numotion and National Seating and Mobility. Both are owned by private equity firms that seek to increase profits and cut spending. One way they do that is by limiting what they spend on technicians and repairs, which, when combined with insurance and regulatory obstacles, frustrates wheelchair users seeking timely fixes.

The \$70 billion durable medical equipment market has been an attractive target for private equity investment because of the aging U.S. population, the increasing prevalence of chronic conditions, and a growing preference for older adults to be treated at home, according to the investment banking firm Provident Healthcare Partners. Medicare’s use of competitive bidding favors large companies that can achieve economies of scale in manufacturing and administrative costs, often at the price of quality and customer service.

Regulations set by Medicare and adopted by most Medicaid and commercial health plans have led to lower-quality products, no coverage for preventive maintenance, and enough red tape to bring wheelchairs to a halt.

Power wheelchair users have long been fighting for the right to repair their wheelchairs themselves or through independent repair shops. Medicare and most insurance companies will replace complex wheelchairs only every five years. The wheelchair suppliers that have contracts with public and private health insurance plans restrict access to parts, tools and service manuals. They usually keep a limited inventory of parts on hand and wait until health plans approve repair claims before ordering parts.

Some chairs require a software passcode or a physical key for any repairs. Wheelchair users who make fixes themselves may void their warranty or lose out on insurance payments for repairs. “What bothers me is that the wheelchair company, knowing that the buttons wear out, won’t keep any in stock,” Bolduc said. “They’ll risk my husband’s life, but they won’t risk \$20 to buy a button and not get reimbursed for it.”

That could soon change. The Colorado legislature has passed a first-in-the-nation right-to-repair bill for power wheelchairs that will allow owners and independent repair shops to access parts, embedded software, tools and documentation needed to perform diagnostic, maintenance or repair services. Colorado Gov. Jared Polis signed the bill into law this month.

The right-to-repair bill may help, said Mark Schmeler, an associate professor of rehabilitation science and technology at the University of Pittsburgh, but it’s not a perfect solution. “There is a serious problem with wheelchair repairs, and the consumers are basically crying out for help,” he said. Part of the problem, Schmeler said, is a Medicare decision not to cover preventive maintenance for power wheelchairs. Many wheelchair users are unfamiliar with or unable to do routine maintenance such as tightening the bolts or cleaning the casters. As a result, problems aren’t addressed until something breaks down, often leaving the user stranded.

Additionally, Medicare officials have interpreted the statute establishing payment for durable medical equipment to cover wheelchairs only for in-home use. Consequently, many power wheelchairs aren’t designed for outdoor

use and are prone to failures when users take them outside. “It’s like you’re outside walking around all day with your slippers on,” Schmeler said.

When Medicare adopted competitive bidding for durable medical equipment in 2011, it allowed large companies to undercut the pricing of smaller, local wheelchair shops. Numotion and National Seating and Mobility bought out many smaller companies and now dominate the market.

Competitive bidding encourages suppliers to press manufacturers for lower-cost wheelchairs, which spurs manufacturers to use lower-quality parts. More than 1 in 4 repairs result in users being stranded, missing a medical appointment, or missing work, according to a study published in 2016 in the journal Archives of Physical Medicine and Rehabilitation.

Wheelchair suppliers make most of their money by selling the wheelchair and tend to lose money on repairs. So there is little incentive to hire more technicians or pay for training.

Suppliers testified against the Colorado bill. “The problem with this legislation is that it does not provide a good solution to address the problems responsible for the delays,” said Seth Johnson, senior vice president of government affairs for Pride Mobility Products, a Duryea, Pa.-based supplier of power wheelchairs. If repairs are done incorrectly, he said, patient safety could be jeopardized.

Medicare regulations add to the problems, with low reimbursements, and Medicare pays only for parts and labor, not for technicians’ travel time. Another cause for delays: Medicare sometimes requires physicians to document that an individual still needs a wheelchair and that it needs to be repaired.

Kenny Maestas of Lamar, Colo., has been in a wheelchair since his spine was severed during a rollover vehicle accident in 1987. His wheelchair supplier, located more than 150 miles away, won’t schedule a repair visit unless it has another client nearby that needs a repair. When his battery begins to die and won’t hold a charge, he becomes tethered to an outlet, unable to leave his home for more than 20 to 30 minutes at a time until the supplier replaces the battery.

“It’s such a broken system,” Maestas said.

Julie Jennings, 56, of Denver, was diagnosed with multiple sclerosis in 1995 and now can’t walk.

She described a lengthy ordeal to get even a simple wheelchair fix — the supplier waited for insurance to approve the repair before ordering the parts. The last time she needed a repair visit — to replace the battery, armrests and a joystick controller — the entire process took three months.

“I try to be proactive, and I try to keep an eye on the wear and tear,” she said.

The right to repair could help reduce the kind of delays that Maestas and Jennings have experienced by allowing users to purchase the parts and repair the wheelchairs themselves or to call in independent repair shops.

Consumer advocates with the Colorado Public Interest Research Group said the power-wheelchair industry is the first sector required to provide repair access since Massachusetts voters approved a right-to-repair measure for cars through a 2012 ballot initiative.

Car manufacturers decided they didn’t want to fight that battle in all 50 states and opted to apply the same standard across the country.

Don Clayback, executive director of the National Coalition for Assistive and Rehab Technology, an industry group representing wheelchair suppliers, said whether the industry would change its policies nationwide was unclear. “We would expect changes will be limited to Colorado,” he said.

Last year, President Joe Biden issued an executive order that directed the Federal Trade Commission to draft regulations that limit manufacturers’ ability to restrict independent repairs of their products. At least three right-to-repair bills have been introduced in Congress this year. Massachusetts and Pennsylvania are also considering bills that address wheelchair repairs.

For now, Bolduc is prepared to go to any length to get her husband’s chair repaired. Once, she took away an uncooperative technician’s keys until he fixed the wheelchair. She then returned his keys and gave him a big candy bar to smooth things over.

“They’ll turn me into this crazy woman because my husband’s life is on the line,” she said. “If I have to kidnap somebody to get his chair fixed, I’ll do it.”



JULY 4th FIREWORKS NEAR YOU

Lawrence Township Fireworks **Rider University** July 1, 9:30 p.m.

Hamilton Township Fourth of July Fireworks & Concert **Veterans Park, Hamilton**
Friday, July 1, 6 p.m. to 10 p.m. Fireworks begin at 9:30 p.m. Rain date, Saturday, July 2.

East Windsor Township Independence Day Celebration **Etra Lake Park**
July 2, 6 p.m. onwards. Rain date is July 9. Fireworks display begins at 9:30 p.m.

Trenton area: July 4 Spectacular at **Arm & Hammer Park**, Trenton. Celebrate Trenton Thunder's 4th of July Spectacular with postgame fireworks and a street party.

Beachwood's Fireworks Over the Toms River Where: **Beachwood Beach**, and beaches in Pine Beach, Ocean Gate and Island Heights along the Toms River. July 4, at dark

Beach Haven: dusk, **Bay Village**, Taylor Avenue, Beach Haven. Rain date is July 5. bayvillagelbi.com.

Brielle: 7:30 p.m., part of the **River Queen boat cruises**, 800 Ashley Ave. Dinner and bar. **Go:** 732-528 6620; riverboattour.com.

Jackson: part of "July 4th Fest," **Six Flags Great Adventure**, 1 Six Flags Blvd., off Route 537. 732-928-1821;

Long Branch: 9:15 p.m., part of 30th annual **Oceanfest**, which runs 10 a.m. to 10 p.m., with musicians, dancers, kids rides, sand sculpting, crafts, food vendors. 732-222-0400; oceanfestnj.com.

Point Pleasant Beach: **Jenkinson's beach**. Fireworks continue every Thursday through Sept. 1, **Go:** 732-892-0600 or jenkinsons.com.

Seaside Heights: 9:30 p.m., **boardwalk**. Also every subsequent Wednesday through Aug. 24. **Go:** exit82.com.

Woodstown: Gather at dusk for food, music and a spectacular fireworks display! The fun begins at 5:00 PM at the **Marlton Recreation Park** in Pilesgrove, NJ.

Atlantic City: The breathtaking 4th of July firework displays over the **waterfront Boardwalk** and the **Marina** are among the most popular Fourth of July events in New Jersey.

Camden County's Freedom Festival: **Wiggins Waterfront Park**. Presented by the Camden County Board of Freeholders and the City of Camden, this festival brings thousands of people together to enjoy a series of artists