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Workforce Crisis In IDD Sector Costing Millions

By **Brendan J. Lyons**, reprinted from *Times Union/TNS* | September 16, 2022

ALBANY, N.Y. — A staffing crisis at residential facilities that serve those with intellectual and developmental disabilities is costing more than \$100 million a year to handle the fallout from the flood of individuals leaving those jobs, according to a recent survey conducted by New York Disability Advocates.

The survey captured more than 50% of the industry's stakeholders, confirming that low pay and difficult working conditions are exacerbating the widespread closure of facilities, including many run by the state Office for People with Developmental Disabilities. "The statistics are rather sobering," said Erik Geizer, CEO of the Arc New York, the state's largest nonprofit organization serving people with intellectual and developmental disabilities.

Geizer noted that there is a 35% annual staff turnover rate and that is being compounded by the roughly 20% vacancy rate for the "direct support professionals" who provide the unique services. In addition, 40% of providers have closed or reduced programs in the past several years. "That's pretty sobering because the number of people with intellectual and developmental disabilities is pretty stable. It's not going down," he said. "This is as bad as I've seen the field. I've never seen things so bad."

Geizer said the quality of care is also suffering as a result of the labor shortage — in an industry where clients do better when the workers helping them are familiar faces. The program shutdowns also have led to many parents and caretakers of individuals with developmental disabilities needing to quit their jobs to care for their loved ones.

With so many workers leaving the industry — where the rate of pay is in line with fast-food restaurants and retail stores — the additional costs of retraining new workers, including many of whom may not remain in the jobs, is depleting the limited amount of money set aside for caregiving.

According to the Public Employees Federation, OPWDD's civil service workforce declined by more than 10,000 workers — to just under 20,000 — between 1990 and last year. In the past three years, 130 OPWDD-operated group homes across the state were "temporarily suspended" due to staff vacancies, the agency said. Group home workers have said mandatory overtime has contributed to additional departures — retirements and resignations — and it's not unusual for some employees to be required to work shifts of more than 30 hours.

In addition to paying out more than \$1 billion in bonuses to workers employed by nonprofit providers — money from the American Rescue Plan Act — the state agency also has added a 5.4% "cost-of-living adjustment for nonprofit provider agencies to address inflation and other fiscal pressures, such as the need to enhance direct care, support and clinical staff compensation." But stakeholders in the industry say those measures have not led to any significant shifts in the workforce crisis.

Kohl's Unveils Clothing Collection For Adults With Disabilities

Reprinted from Disability Scoop by Shaun Heasley | September 14, 2022

Three years after introducing a line of sensory-friendly and adaptive clothing for kids, a major national retailer is adding options for adults with disabilities too.

Kohl's said this week that it will offer adaptive products for adults through three of its biggest private-label brands.

"Kohl's is proud to expand our adaptive assortments and offer inclusive collections for the entire family," said Ron Murray, interim chief merchandising officer for the company. "At Kohl's, we understand how important it is to ensure all of our customers and associates are able to celebrate their personal style and independence in a way that meets their individual needs. Our adult adaptive collection is about creating apparel that is accessible to everyone, regardless of age or ability, and serving more of our customers with disabilities."

Women's adaptive offerings will be available from Kohl's Sonoma Goods for Life, Tek Gear and SO brands, the retailer said. Men's products will be sold under the brands Sonoma Goods for Life and Tek Gear as well as Tommy Hilfiger.

All of the pieces are designed to be comfortable and to make it easier for people with disabilities to get dressed independently, Kohl's said.

Products in the collection include everything from leggings and jeans to long-sleeve tees, jackets and sweatshirts. They offer special features like wider necklines, functional leg openings and the ability to adjust the waistline for seated comfort.

Kohl's said it worked with GAMUT Management, a talent management company for people with disabilities that also consults with businesses on how to serve this population, to develop the new line and hold focus groups with people with disabilities.

"By listening to customers across the country, Kohl's innovative design team was able to create new apparel that provides new options for adults with disabilities and we look forward to continuing to expand in this market to address the growing needs of our customers," said Michelle A. Banks, chief diversity and inclusion officer at Kohl's.

Officials with the company said the expansion into adult adaptive products follows the success of Kohl's children's offerings, which were first introduced in 2019 and now include apparel, shoes, costumes and toys.

Retailers have increasingly offered adaptive clothing in recent years, with most focusing on products for children. Target and Zappos are among those that have also sold apparel aimed at adults with disabilities.



Adaptive styles for kids and adults are now available on Kohl's website.

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Rule Change Could Improve Access To Dental Care For People With Disabilities

Reprinted from *Disability Scoop* by Michelle Diament | August 29, 2022



Dentists say bureaucratic issues are forcing children and adults with disabilities across the nation to unnecessarily wait six to 12 months for care, but a fix could soon be on the way.

Three leading dental groups wrote to the Centers for Medicare & Medicaid Services earlier this summer citing “significant concerns” about access to dental procedures in hospitals and similar settings.

“The lack of (operating room) access for needed and covered dental procedures often results in wait times of 6-12 months for these patients, many of whom are children whose daily activities and school performance are often significantly affected in the interim,” wrote officials from the American Academy of Pediatric Dentistry, the American Dental Association and the American Association of Oral and Maxillofacial Surgeons.

“We attribute most of this access challenge to the lack of a sustainable billing mechanism for hospitals and (ambulatory surgical centers) to report dental surgical services in both Medicare and Medicaid,” the groups indicated.

Specifically, they said that with the existing billing code that hospitals use for dental patients who require operating room access, Medicare provides a rate of just \$203.64, far short of the \$2,334.87 average cost for such services. As a result, the dental groups contend that hospitals are reluctant to schedule their surgical cases.

Meanwhile, current Medicare regulations do not allow for coverage of dental surgeries at ambulatory surgical centers, which dentists say could help to alleviate pressures stemming from the lack of access to hospital operating rooms.

The impact is widespread, the letter notes, since Medicaid programs often model Medicare rates and both Medicaid and commercial insurance typically follow Medicare’s lead to determine what to cover.

“Limitations in access have been exacerbated by the COVID-19 pandemic, primarily affecting high-risk Medicaid and commercially insured patients who, due to their particular medical conditions and other circumstances, require an operating room (OR) setting for the performance of extensive dental procedures,” the groups wrote to CMS.

Similar concerns have been raised by the Consortium for Citizens with Disabilities Health Care Task Force, the American Academy of Pediatrics and members of Congress.

Now, CMS is working to make changes. Under a new proposal, the agency plans to update the Medicare code that hospitals use to bill for dental procedures in operating rooms. The new code would allow for a payment rate of \$1,958.92.

Dr. Jane Grover, senior director of the Council on Advocacy for Access and Prevention at the American Dental Association, said that if approved the CMS proposal “would take a significant first step forward toward improving access to needed dental surgeries for children and adults with disabilities.”

In addition, Grover indicated that “the dental community is continuing to advocate for reforms that would help to ensure there is sufficient operating room capacity to support dental surgical access for disabled patients served by Medicare and Medicaid.”

The proposed rule is up for public comment through Sept. 13. If finalized, the changes would take effect Jan. 1.

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From Norman's Desk

September Was Suicide Prevention-Awareness Month *It can be difficult to talk about suicide.*



The stigma around mental health conditions and suicide can be an overwhelming barrier people encounter when trying to talk about suicide, and data shows that most people who experience suicidal thoughts do not seek professional help. Stigma can come from families, peers, and society as a whole. Someone may stay quiet because of the fear of being labeled "crazy" or they worry about being a burden to others. Others may be afraid to discuss it because they believe the incorrect idea that discussing suicide could plant the idea in someone's mind. Others may fear being socially rejected.

If you are in immediate danger of harming yourself or if you know someone is immediate danger of harming themselves or others, call 911 immediately.

If you do not suspect an immediate threat or danger, asking someone questions and/or letting them know you are there for them might be enough to convince them to get help. Some things you could say include:

- "I have noticed some behaviors that are concerning me. I care about you. Please tell me what you are thinking about."
- "It sounds like things are really rough right now, and I'm worried about you. Are you thinking of harming yourself?"

You are not alone. I am here for you. We will get through this together."

The most important things you can do are to listen and ask questions in a nonjudgmental way.

These are some possible warning signs of suicide:

- Talking about feeling hopeless or having no reason to live
- Talking about feeling trapped or in unbearable pain
- Increased alcohol and/or drug use
- Aggressive behavior
- Withdrawal from family, friends, and community
- Dramatic mood swings
- Talking about wanting to die
- Looking for ways to kill oneself, such as searching online, buying a weapon, or collecting and saving pills
- Impulsive or reckless behavior
- Giving away possessions
- Saying goodbye to friends and family

Please remember that help is always available. Crisis support lines include:

988 Suicide & Crisis Lifeline (formerly the National Suicide Prevention Lifeline): You can call, text, or chat by dialing the three digits 988 or you can call 800-273-8255 (TALK). You also can go to 988 Suicide & Crisis Lifeline's web page and chat. Spanish-speaking people can call the Lifeline at 888-628-9454. Veterans can call 988 and then press 1 to be connected to the Veterans Crisis Line. TTY users can use their preferred relay service or dial 711 then 988.

Crisis Text Line: if you are uncomfortable speaking on the phone, you can text 741741, and your opening message can say anything, even something simple like "hello."

Psychiatric Screening Services at Capital Health Regional Medical Center: 609-394-6086 Provides 24/7 psychiatric screening for Mercer County residents. Suicidal, homicidal and psychotic youth are evaluated and level of care recommendations will be provided. Inpatient treatment, if recommended, will be facilitated. If outpatient is recommended, youth will be referred to MRSS. The child's legal guardian must be present for evaluation.

For more information on the Mercer County Division of Mental Health and/or the services it funds for Mercer County residents, please call 609-989-6574, email mmadiou@mercercounty.org, or visit the office's web page.

Disability Community Wants More From Trenton, Commemorates COVID Deaths

Reprinted from NorthJersey.com by Gene Myers, Tue, September 20, 2022 at 3:39 PM

The disability community and its advocates met in Trenton on Monday to commemorate people with disabilities who died of complications from COVID.

A small group of people commiserated outside the Statehouse. “We lost a lot of people,” said Javier Robles, a Rutgers University professor and organizer of the event. “If we had some better precautions in place, a lot of them would still be here today. We have to change a lot of our thinking around people with disabilities.”

Over 200,000 residents and staff members in long-term care facilities in the U.S. have died from COVID-19, according to the Kaiser Family Foundation, a nonprofit organization that focuses on national health issues. That’s a low estimate, Robles said, because disability stats aren’t reliably collected.

One speaker for whom the loss was all too real was Regina Costantino Discenza, who lost both of her parents during the pandemic. Both were residents of the Menlo Park Veterans Memorial Home. “My father passed away about 30 days after the families were locked out,” she told the crowd, referring to their isolation. “I knew my parents weren’t going to survive without my visits. They were disabled with dementia.” Both were diagnosed with COVID-19. Although her mom survived COVID, she died six months after her husband.

Paul Aronsohn, the state ombudsman for individuals with intellectual or developmental disabilities and their families, called the ceremony “an important event.” “Professionally as well as personally I have witnessed the disproportionate and sometimes devastating impact COVID has had on people with disabilities,” Aronsohn said. “This includes my brother, Robert Zuckerman, whose disabilities landed him in a Florida nursing home, where he contracted the deadly virus this past summer and died from it only days later.”

Aronsohn’s 2020 report to Gov. Phil Murphy stated “the pandemic has exposed and deepened the fault lines in our state’s system of care for people with disabilities.”

Now, as a chill returns to the air, the community wants leaders to make changes to the emergency response apparatus that failed them, before winter sets in and another variant or public emergency hits.

The New Jersey Disability Action Committee (DAC), New Jersey Statewide Independent Living Council, Alliance Center for Independence, New Jersey Disability Collective, New Jersey Council on Developmental Disabilities and Latino Action Network were in attendance.

They took turns at the podium remembering injustices, loved ones and colleagues lost. First, people with disabilities were left out of emergency planning in the pandemic’s first wave. Then came the scramble for protective gear as the state advised the community that it was on its own. Disability advocates warned of discriminatory care practices in hospitals while state policymakers failed to recognize who was most vulnerable in the health emergency. Millions were vaccinated ahead of the relatively small group of about 9,000 people living in homes overseen by the state.

Robles, who spearheaded the DAC, which published a scathing report in 2020 that outlined the ways in which the state failed to protect its disabled residents, said if there was one underlying theme in all of these problems it was that leaders didn’t understand people with disabilities, their needs or how they live their lives, Robles said. Representatives of the community “should be at the table” when planning for emergencies, he said.

Last year, the DAC called for establishing four full-time positions at the state Office of Emergency Management devoted to the needs of people with disabilities in emergencies and disasters. The bill has been reintroduced in the state Legislature this year.

Gene Myers covers disability and mental health for NorthJersey.com and the USA TODAY Network. For unlimited access to the most important news from your local community, please subscribe or activate your digital account today. Email: myers@northjersey.com Twitter: [@myersgene](https://twitter.com/myersgene)

As Institutions Close, Families Of Longtime Residents Face Agonizing Choices

By Tony Leys, reprinted from Kaiser Health News | September 21, 2022

GLENWOOD, Iowa — Mike Lee's way of life has faded away in most of the United States, and it soon will vanish from southwestern Iowa. Lee, 57, has spent 44 years at the Glenwood Resource Center, a state-run institution for people with intellectual or developmental disabilities. He has autism and epilepsy, and his parents decided when he was 13 that he needed the structure and constant oversight offered by a large facility. That was a common decision at the time. It no longer is.

The number of Americans living in such institutions has dropped more than 90% since the late 1960s. Seventeen states have closed all their large public institutions for people with disabilities. Just five states — Iowa, Nebraska, South Carolina, Utah and Wyoming — haven't closed any, according to a University of Minnesota expert. Iowa announced in April that in 2024 it would shutter the Glenwood Resource Center, a sprawling campus near the state's western border. State leaders cited federal pressure to improve conditions for the facility's residents or place them elsewhere.

Many of the remaining residents of such places have lived there for decades, leaving their families with wrenching choices when closures loom. Lee knows he will move soon, even if he doesn't understand all the implications. His sister, Connie Bowen, broached the subject during a recent visit. She picked her brother up from the one-story house where he lives with several other residents on the institution's grounds and drove him to a nearby Pizza Hut for lunch.

As he sipped on a root beer, she asked how he felt. "Does it make you sad or happy that you're leaving?" she said. "Happy! I'm happy," he replied.

Bowen, who is her brother's legal guardian, agrees in theory with the idea of caring for people with disabilities in homes or apartments. But like many other relatives of Glenwood Resource Center residents, she worries that the new arrangements might not be safe for people who have been institutionalized for decades.

The Glenwood Resource Center, founded as an orphanage in the 1860s, housed more than 1,900 people at its peak in the 1950s. Now, 134 people live there. Many residents face more hurdles than Lee does. Some can't speak. Many also have physical disabilities that make getting around difficult and can pose life-threatening risks. Some residents can become confused or agitated.

The closures partly stemmed from the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C.*, which held that Americans with disabilities have a right to live in the least restrictive setting that is practical.

Like Glenwood, most state institutions opened more than a century ago, and they typically were constructed in rural areas. "There was a movement to create a bucolic environment for individuals," said Mary Sowers, executive director of the National Association of State Directors of Developmental Disabilities Services. Many of the big institutions included farms, where residents helped grow their food. Conventional wisdom held that country life would be healthful. Now, Sowers said, "we recognize that the larger settings really didn't wind up living up to that promise, and individuals are able to thrive more when they're able to live in communities."

Sowers said about 1.3 million Americans are served by public programs for people with intellectual or developmental disabilities. Only about 1% of them live in large state institutions. Larson said families of the institutions' remaining residents may feel whipsawed by experts' advice.

Years ago, medical professionals told parents that their children could best be served in such places. Now, those same families are urged to move their loved ones out. "They did what they thought was the right thing to do — and now to be told it wasn't the right thing to do is really, really hard for them to accept," she said.

The transition away from institutions for people with intellectual or developmental disabilities has been handled better than the wave of state mental hospital closures over the past 50 years, Larson said. Critics contend that as large state mental hospitals were shuttered, they weren't replaced with sufficient community services. That

sparked a surge in people with untreated mental illnesses living on the streets or in jails and prisons. Facilities like the Glenwood Resource Center serve people with intellectual disabilities, such as severe autism and brain injuries. Larson said that community services for people with intellectual disabilities have increased and that surveys find most families are satisfied with the results after their loved ones move from institutions to community placements.

Scandals Preceded Closure

The Iowa closure decision came after a series of scandals at the Glenwood Resource Center. Allegations included that insufficient medical care led to several deaths and that administrators planned unethical research on residents. Top administrators were ousted, and the U.S. Justice Department began investigating as allegations of poor care continued.

In the scandal's wake, Iowa leaders assured residents' families that they had no plans to close either of the state's two institutions for people with disabilities. But the message abruptly changed in April, when state officials announced the Glenwood Resource Center would close. They cited the high cost of complying with federal expectations if it were to stay open. The state and federal governments spend about \$392,000 per resident annually at the institution.

Kelly Garcia, Iowa's director of health and human services, said she understands that contemplating a move can be stressful for residents and their families. But she said Iowa clung too long to an outdated role for such institutions. "This notion that you are admitted at age 2 and you live 80 years there is no longer the way we as a society would want to support a human being," she said. She said the state is committed to providing money and expertise to the private agencies that will support former Glenwood Resource Center residents.

Garcia said the state's commitment is one reason more than 30 agencies showed up in July for a "provider fair" in the institution's gym. Residents' families and guardians met with private care providers and considered their options. Crest Services, a residential care company for people with disabilities, sent representatives to the event. Director Bob Swigert said in a recent interview that his agency is looking to arrange community placements for 10 residents of the Glenwood Resource Center. The main hurdle has been finding suitable housing for the residents, including those who use wheelchairs, Swigert said. His company might retrofit some homes for that purpose.

Swigert said he and his staff are reassuring residents' families that they will continue to have necessary services, including round-the-clock staffing. "They're concerned, they're anxious — which is very understandable," he said. "These individuals are being required to move from what has pretty much been their lifetime home." The institution's 380-acre campus includes numerous ranch-style homes, where residents live with oversight from staff. It has several large old buildings, from days when people with disabilities were warehoused. It also includes a fire station, a greenhouse, a water tower and a cemetery containing the graves of hundreds of people who have died at the institution since the 1800s.

The facility has been a vital part of life in Glenwood, a town of about 5,000 people near the Missouri River. The institution has nearly 470 workers, making it the largest employer in the area, with relatively good wages and benefits. Two or three generations of many local families have worked there. "Some of the institution's residents will never understand the situation.

One is Seth Finken, 43, who has lived at the Glenwood Resource Center since 1984. Childhood meningitis damaged his brain and left him blind, deaf and medically fragile. His mother, Sybil Finken, lives in the town of Glenwood and sees few options for her son in the region. The most advanced care programs she has talked to are in bigger cities, such as Des Moines or Dubuque. "This is Seth's community," she said. "I don't want him moving two or four hours away."

For years, Sybil Finken called for Iowa to keep operating the Glenwood Resource Center. She knew most other states had closed institutions for people with disabilities. She figured Iowa would follow suit eventually, but she believed assurances that longtime residents could live out their lives there. Now, she said, all she can do is keep talking to private care agencies and hope someone figures out how to keep her son safe in a community setting. "Seth and I are going to be the last ones out the door," she said.

Can Artificial Intelligence Detect Autism Doctors Miss?

Reprinted from Disability Scoop by Teddy Rosenbluth, The News & Observer/TNS | September 20, 2022

When most toddlers diagnosed with autism sit still, their heads sway very slightly back and forth. That movement is an extremely reliable way to distinguish between a neurotypical child and a child with autism, research has shown. But it's almost imperceptible to even a seasoned clinician.

For a computer trained to see it, though, the movement is obvious. "A computer just gives you a beautiful readout of how many times the head moves back and forth," said Geraldine Dawson, director of Duke University's Center for Autism and Brain Development. Dawson and her colleagues are testing an app that Duke has patented to harness that power. It uses artificial intelligence to analyze toddlers' movements, eye positions and facial expressions, among other things, to help predict who has autism. Children with autism display a number of subtle behaviors like the head tilt that can be used to accurately diagnose kids early, Dawson said. When they're watching a video, for example, they spend less time looking at the people on the screen than their neurotypical peers.

Using a recently awarded \$12 million National Institutes of Health grant, Dawson's lab will test the digital app to see whether computers can offer a more accessible and objective way of diagnosing autism. The app displays short videos designed by the researchers to gauge toddlers' social interest on a phone screen. At the same time, it observes a child's movement and marks behaviors associated with autism in real-time. "By using a computer, you're using a very objective technique that is able to really pick up on the subtleties in a way that's much more reliable," Dawson said of the app, which is not yet used by clinicians.

Earlier is almost always better when it comes to autism intervention. Early treatment is often associated with a higher IQ and a higher likelihood the child will be able to learn in a traditional school setting, Dawson said. "It is so effective, especially when it's done early, that many children no longer meet diagnostic criteria for autism," said Dr. Theresa Flynn, vice president of the North Carolina Pediatric Society.

Yet, not all children receive early diagnoses or therapy. Black children are typically diagnosed with autism three years after white kids in the United States. Girls are diagnosed about a year and a half later than boys, on average. The differences are partly due to health care access disparities, Dawson said. Children that don't go to the doctor don't get screened for autism. Dawson said she hopes the Duke app, which can be used to capture data in clinics and homes, could help make this process more accessible to those families. "The remarkable thing is the fact that we're really just using a smartphone," she said. "There's no equipment, no research assistant or physician or anything."

Many researchers, including Dawson, believe disparities in diagnosis are partly due to a flawed screening system that relies on measures susceptible to human bias. Primary care providers typically screen toddlers for autism using a 20-question survey that asks questions of parents like: "Does your child play pretend or make-believe?" and "Is your child interested in other children?"

While survey-based screening is important, it has clear blind spots, Dawson said. One study involving 26,000 children, found that the survey is not as accurate in girls, children of color and those from lower-income households. Artificial intelligence circumvents some of those biases by focusing more on objective measures, like eye position, rather than a parent's interpretation of their child's behavior, Dawson said.

Flynn, the North Carolina Pediatric Society vice president, noted however that no computer algorithm is truly objective. One study published last year in *Nature Medicine* found that an algorithm used to screen chest X-rays routinely missed signs of disease in female, Black and Hispanic patients, labeling them incorrectly as healthy. Other researchers have raised concerns that algorithms tasked with detecting skin-cancer, many of which are primarily trained using photos of white patients, might do worse at detecting the cancer on Black patients.

Dawson said her research has shown that the autism app's algorithm is equally good at identifying autism-related behaviors in kids of different races and ethnicities. In future experiments her lab will test whether this holds true in a larger population, she said. Dr. Kristin Sohl, who heads a subcommittee on autism for the American Academy of Pediatrics, said there's a certain amount of human expertise that's still essential for diagnosing autism. "While these tools are great, I still think there's an overlay of that clinical judgment that's required," she said.