March 2022

New Horizons

Housing That Supports Independence

36th Anniversary
Project Freedom Inc

Doctors Know Little About Their Obligations To People With Disabilities, Study Finds

By Michelle Diament / reprinted from Disability Scoop / January 11, 2022

Three decades after the Americans with Disabilities Act took effect, new research finds that many physicians remain unaware of their obligations under the law when caring for people with disabilities.

More than a third of doctors surveyed had little or no knowledge about their legal requirements under the ADA and 71% did not know who determines reasonable accommodations.

The findings come from a survey of 714 doctors in outpatient practices across the nation that was published this month in the journal Health Affairs. “Despite the fact people with disabilities comprise 25% of the population, they often confront barriers to basic health care services such as physical examinations, weight measurement and effective communication with their physicians,” said Dr. Lisa I. Iezzoni of Harvard Medical School and Massachusetts General Hospital, the lead author of the study. “The lack of knowledge about who makes accommodation decisions raises troubling questions about health care quality and equity.”

The ADA bars discrimination against people with disabilities, including in medical services. Under the law, health care providers must work with patients to decide what reasonable accommodations are needed in order for individuals with disabilities to receive proper care. Iezzoni said that people with disabilities should inquire about how doctors can address their needs when scheduling an appointment. Doctor’s offices should document needed accommodations within patients’ electronic health records and ask each time a new appointment is scheduled if a person’s needs or preferences have changed, she said.

Studies show that people with disabilities often receive substandard care, with individuals examined in their wheelchairs rather than on exam tables and those who are deaf going without sign-language interpreters, for example, the researchers said.

The latest survey suggests that at least some physicians are concerned with 68% indicating that they believe they are at risk for ADA lawsuits. The findings highlight the need for improvements in medical training, according to those behind the study.

“Medical schools are currently training students about combating racism, and there should also be training in combating discrimination against people with a disability, also known as ‘ableism,’” said Eric G. Campbell, a survey scientist at the University of Colorado and a senior author of the study. “Every practicing physician can expect to see increasing numbers of people with disability, and they need to know how to accommodate them.”

Actor With Disability Scores Historic Oscar Nomination

Reprinted from February 11, 2022 Disability Scoop / by Shaun Heasley

Troy Kotsur and Marlee Matlin star as deaf parents in "CODA." Matlin was the first deaf performer to win an Academy Award and Kotsur is now the first deaf male actor to be nominated. (Apple TV+)

A film prominently featuring people with disabilities is making history with multiple Academy Award nominations.

"CODA" became the first film starring a mostly deaf cast in leading roles to be up for best picture when the nominations were announced this week.

In addition, Troy Kotsur, who stars as a fisherman and family patriarch in the movie, became the first deaf male actor to receive a nomination with his nod for best supporting actor. And, the Apple TV+ movie was nominated for best adapted screenplay.

"CODA," which stands for child of deaf adults, centers on 17-year-old Ruby who is the only member of her family who can hear. Ruby often acts as an interpreter for her parents, played by Kotsur and Marlee Matlin, and is divided between her family obligations and her desire to pursue her own dreams as a singer.

Kotsur told the Los Angeles Times that he was inspired by his "CODA" co-star Matlin who was the first deaf performer to win an Academy Award in 1987.

"It's a tough journey as a deaf actor," Kotsur told the newspaper. "There's so few opportunities out there, and she kept on going. She was persistent. And then so was I with my own career as a stage actor. So here I am today."

The winners of the Academy Awards will be announced March 27.

Clock Ticking For Youth With Disabilities Likely To Lose Their Group Homes

***Article reprinted from NJ.com/TNS | January 31, 2022 by Susan K. Livio** © 2022 Advance Local Media, LLC*

ISELIN, N.J. — For a young man with autism, bipolar depression and handful of other medical conditions that require constant monitoring, 18-year-old Aidan Burke is always smiling, his mother says. He's willing to eat the healthy meals that are planned for him, enabling him to lose more than 100 pounds. And although he is nonverbal, Aidan is learning to communicate using a "talker," a tablet-like device with pictures, his mother, Johanna Palestini Burke said. These positive changes in her son's life can be attributed to the patient staff at his group home in Sicklerville, where he has lived since 2018, and the skilled professionals at the Durand School in Woodbury, Palestini Burke said. That's what made the announcement six weeks ago that her son's group home is closing so terrifying, she said.

Oaks Integrated Care intends to close five group homes in south Jersey serving 24 children and young adults with developmental disabilities, "due to staffing challenges faced by our agency," Oaks spokeswoman Denise Soto wrote in an email. Oaks had intended to close the homes by the end of this month, but will keep them open until everyone is placed, the company said.

Since the announcement was made almost two months ago, officials from Oaks and the state Department of Children and Families say they have been searching for a new provider to assume control of the properties, with no success yet. It's more likely these residents will be sent to different facilities, which may also disrupt where they go to school if they are relocated far away.

Suzanne Buchanan, executive director of Autism New Jersey, a research and family advocacy organization, said she hasn't heard about other group home operators shutting down. But difficulties filling jobs working with people with challenging behaviors, and getting paid for little more than minimum wage, is nothing new.
"The job can be physically and emotionally demanding. You need the right motivation, energy and skill set. And maybe after a few years, they move on," Buchanan said. Shutting down a program will undoubtedly cause upheaval, she said. "Our immediate reaction was sadness for the children themselves. Their lives and routines — everything going on in their day — their whole world will be turned upside down again," Buchanan said. "Families are in crisis prior to a placement like this."

Families are already on a waiting list for housing. More closures "extend the wait times," Buchanan said. "We certainly don't have the capacity we need in the state. It's a national problem."
Oaks closed two group homes for youth in 2021 — the Perkins home in Edgewater Park and Fish Pond 1 in Glassboro, the company confirmed. "The group homes were closed due to pandemic-related staffing challenges. We worked with our state partners and families/guardians to identify placements for each resident," Soto said. At the time of the Perkins home closure, local police and the state Children and Families department were investigating a report of a staff member assaulting a 22-year-old resident in May. Oaks informed the state it wanted to shut down the five homes by Jan. 31 because they did not have the "middle management and clinical staff" necessary to oversee "the provision of care," Children and Families spokesman Jason Butkowski said.

Oaks intends to close the Archertown group home in New Egypt, Fish Pond II and III in Glassboro, Kearsley in Sicklerville and Perkins, which reopened for adult clients after the contract for youth ended over the summer, Butkowski said. Oaks will continue to hold a state contract for three other group homes serving 15 youth and young adults, he added. Various state agencies and the New Jersey Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families are "develop(ing) a plan to move forward with the least disruption possible," Butkowski said.

Whenever 16-year-old McKenna Cree is relocated from the Archertown group home, it will be the fourth time she has moved since 2015, her mother Michelle Cree of Toms River said. Two of those moves occurred just last year, when Oaks closed Perkins and Fish Pond I, she said. She recalled that Fish Pond I shuttered "on the heels of a (state) investigation," but she didn't know the details.

"There were some great staff at Oaks that she spoke highly of," Cree said. "They are working very hard and working a lot of overtime because of (staff) shortages." The state has found a new home for McKenna: a group home called Crossroads located in Cherry Hill. Crossroads has promised to provide McKenna more behavioral therapy — services Oaks did not provide consistently, so Cree said she is hopeful this will be a better fit for her child. But there are trade-offs. It's farther from home, which will make visiting harder.

The move is on hold until this latest wave of coronavirus cases recedes, Cree said.

From Norman's Desk

This month is the 38th anniversary of Project Freedom's incorporation as an organization in New Jersey. In the life of any organization that strives to help people, there are individuals who exemplify what the organization's mission is about. Project Freedom has been privileged to honor many over the years, but a few stand apart because of their unique contributions to the organization, the community, or the people around them.

Scott Ellis was one of those individuals. To many of us, Scott was a hero although he would never tolerate that designation or accept many accolades. Scott is one of a handful of Project Freedom tenants who actually inaugurated two of our complexes. He was one of those 30 "pioneers" in 1991 to move into the first Robbinsville complex,. After Scott followed his life's paths away from Project Freedom, he returned to inaugurate the first Hamilton complex in 2001.

Imagine a stereo-typical firefighter and you will have Scott's persona exactly. The guy would give the proverbial shirt off his back, give you a ride miles out of his way, or literally walk into a fire to bring you out. Calm, cool, and self-effacing, Scott was the friend everyone wants in a crisis or on a bad day. I personally made it through a bad day with Scott's help

Firefighting was Scott's life. The Hightstown Fire Department the center of his universe. It was a family tradition that imbued on Scott his sense of duty and service to others. He brought that sense with him to Project Freedom.

After his injury, Scott personified the "dignity of risk" philosophy better than anyone. According to Ibrahim & Davis (2013), "'Dignity of risk' refers to the concept of affording a person the right (or dignity) to take reasonable risks, and that the impeding of this right can suffocate personal growth, self-esteem and the overall quality of life." Scott did not limit the risks that he took to live independently, to help others in need, or because duty called. Risks were meant to taken, and Scott was prepared for the possible negative consequences.

Lives changed after the attacks September 11, 2001, and for Scott the field of "inclusive emergency planning" opened new opportunities to serve the community. Once involved, Scott became a leading expert in New Jersey and nationally on planning for emergencies to include people with disabilities. Scott was recognized by FEMA and was given an award by them at a ceremony at the White House.

Scott Ellis with Norman Smith

Scott was in the Mercer County Community Emergency Response Team (CERT) along with a few other PF tenants and staff from the Progressive Center. Scott worked a number of disasters inside Mercer's Emergency Operations Center as a CERT member, and this led Scott to be the Access and Functional Needs (people with disabilities) Coordinator for Mercer County. He served in that capacity during Super storm Sandy, and knowing Scott, he probably risked his physical health and wellbeing by sleeping in his chair to be able to stay at the operations center. Duty, service, and self-sacrifice... that was Scott Ellis to his core.

Scott Ellis with Scott Elliott

I asked two other colleagues of Scott to share their memories of him. Scott Elliott of the Progressive Center wrote:

Scott and I were not only colleagues but also good friends. It was funny working together since our names and voices were similar; individuals calling the office we're often confused, and we found ourselves clarifying who was who on a regular basis.

Not too long after entering the disability community arena, Scott became a mentor to me in regard to wheelchairs, vehicles and other ideas that assisted him with his independence. His experience was invaluable in helping me and others with a disability live a more independent lifestyle."

Kelly Boyd of the NJ Office of Emergency Management shared:

Scott Ellis with Kelly Boyd

"Scott Ellis was my longtime mentor, colleague and friend. For many years, I turned to Scott for advice related to issues on disabilities, emergency management and just life in general. His sage advice was often spot on, and I will miss visiting him to catch up on the craziness of life.

Although Scott was not usually one to reach out for help, he never failed to support me when I needed it—even giving me rides to work when my van broke down. Scott could always be counted on as a loyal friend.

In fact, if it weren't for Scott and several other colleagues, I would not be working in the emergency management field today. It is a rewarding career, and he taught me much of what I know. For that, I can never thank him enough.

The best way I can honor him now is by using this knowledge to educate and help others for many years to come. As Scott's advocacy lives on, may his soul rest in peace."

We will miss Scott, but his legacy continues every time a person with a disability comes through an emergency with dignity and functionality Rest in Peace, my friend.

Norman A. Smith, Associate Executive Director -
Follow us on Twitter @TheFreedomGuys
"Like" us on Facebook.com/ProjectFreedomInc

The New Jersey Council on Developmental Disabilities' Community Innovation Projects (CIP) encourage new and innovative activity designed to bring about meaningful local change.

Funding up to $10,000 for 12 months is available.

Community Innovation Projects Will:

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

Activities Might Be: **An innovative approach to a systemic challenge OR; An activity that addresses a systemic problem that is being overlooked, OR; An innovative project or pilot project related to the 5-Year plan that demonstrates a best practice.**

Grant Funds Cannot Be Used For: **Direct services (i.e. respite care, camps, travel programs, after school programs) UNLESS that direct service is needed for a proposed activity, (i.e., on-site respite care while parents are being trained; travel program to Trenton for self-advocates to learn about advocacy); OR, the direct service will be provided in an innovative way that meets the criteria above**

If Interested in applying for: **Grant funds to support short-term projects of up to 12 months with requests up to $10,000, please write or email (grants@njcdd.org) a letter of interest including:**

- Who you are?
- What problem(s) you are trying to address?
- How you plan to address it?
  Describe the project goals/outcome. Describe funding level request/use of funds.
- How this relates to the Council's 5-Year plan?

Our review team will let you know if your concept aligns with our vision. If so, we will invite you to complete the Community Innovation Project application form. We look forward to collaborating with you.

Books Honored For Disability Storylines

By Shaun Heasley / reprinted from Disability Scoop / January 28, 2022

New children's books about kids with autism, visual impairment and other disabilities are being recognized alongside top honors like the Newbery and Caldecott Medals.

Three winners and five honorees of the Schneider Family Book Awards were announced by the American Library Association this week.

The awards go to works that "portray the emotional, mental or physical disability as part of a full life, not as something to be pitied." They are given annually to authors and illustrators for books targeting young children, middle grades and teens.

"A Bird Will Soar" and "The Words in my Hands" are among the winners of this year's Schneider Family Book Awards. (Penguin Random House; Annick Press)

In the young children's category, the winning book is "My City Speaks," which gives the perspective of a young girl with visual impairment as she and her father take in their city. The honor books are "A Walk in the Words," about a boy who struggles with reading, and "A Sky-Blue Bench," about a girl with a prosthetic leg.

The winner for middle grades is "A Bird Will Soar," which uses poetry and science to tell the story of a boy with autism who loves birds and learns to help his family, an injured bird and himself. Honor books for this age group are "Stuntboy, in the Meantime" about a boy dealing with anxiety and "A Kind of Spark" about a girl with autism who wants a memorial for the witch trials that happened in her town.

The teen award is going to "The Words in my Hands," which centers on an adolescent who is deaf and is searching for her identity through art and activism. The honor book in that category is "A Face for Picasso: Coming of Age with Crouzon Syndrome," a memoir about life with a rare condition that causes facial disfigurement.

The winners of the Schneider Family Book Awards each receive $5,000 and a framed plaque.

Separately, the Dolly Gray Award, which goes to books for children or young adults that authentically portray autism and developmental disabilities, was also handed out this week by the Council for Exceptional Children's Division on Autism and Developmental Disabilities.

Unpacking Disability
with Meriah Nichols

Reprinted from a blog by Meriah Nichols

Free Stuff for Adults with Disabilities

www.meriahnichols.com

Deshae Lott Quality of Life Grants: "works to help American citizens with severe mobility limitations maintain hopeful, purposeful, engaged lives by providing some financial support for medically-necessary home-health-care services not covered by insurance, private or governmental, and not covered by any other non-profit organization."

Medicaid "The full range of benefits from Medicaid sometimes goes overlooked. They will pay for changes in your house so it is more accessible (5k every 5 years), they offer rides to appointments, reimbursement for travel to appointments, a case worker you can contact directly, and in-home caretaker hours."

Easterseals I feel a little guilty putting this in because the site is so vague and huge. Evidently though, they can be useful? You are supposed to find the branch office close to where you live, and see what they are able to offer you. Sounds like fun!

REquipment Used medical equipment, for free, without hassle from insurance.

Department of Vocational Rehabilitation the point of a DOR/DVR is to help people with disabilities find and keep jobs. If you need some medical equipment (or something along those lines) in order to find and keep a job, they will usually help you. I got my digital hearing aids that way, years ago, and those bub-bas aren't cheap. It's an enormous goal and huge in its variables. Say you need a speech device in order to go to school so you can receive training so that you can be a train operator? = DOR will consider paying for your speech device AND tuition that is not covered by financial aid. A blind stylus? What about an iPad for deaf people, for Facetime/Skype online learning? I mean, DOR covers a lot of stuff, but you need to be able to fit what you are asking into the framework of being able to find and keep a job.

***Center for Accessible Technology**:* they have an iPad loan program (and more, they are awesome, make sure you get to know them).

National Institute on Deafness and Other Communication Disorders Their description of what is out there is comprehensive and pretty accurate. It's a good place to read through, then move on to their list of helpful organizations to reach out to.