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In First, Feds Issue National Strategy To Support Family Caregivers

Reprinted from Disability Scoop by Michelle Diamant | September 22, 2022

Federal health officials are putting forth a national strategy to address the needs of family caregivers, acknowledging the challenges faced by millions who care for people with developmental disabilities and other issues.

The first-of-its-kind plan details 345 actions that 15 government agencies will take in the next three years as well as over 150 actions that can be undertaken by states, communities and other stakeholders.

“Supporting family caregivers is an urgent public health issue, exacerbated by the long-term effects of the COVID-19 pandemic,” said U.S. Secretary of Health and Human Services Xavier Becerra. “This national strategy recognizes the critical role family caregivers play in a loved one’s life.”

There are estimated to be some 53 million family caregivers in the U.S. supporting those with developmental disabilities, individuals who are aging and others. They “provide the overwhelming majority of long-term care” in this country and, if replaced by paid caregivers, their services would cost an estimated \$470 billion annually, according to the Department of Health and Human Services.

Without support, family caregivers can compromise their own health, wellbeing and quality of life, officials note. In addition, caregiving responsibilities result in an estimated \$522 billion annually in lost income for families.

The national strategy released by HHS’ Administration for Community Living this week was developed by the agency’s RAISE Family Caregiving Advisory Council and Supporting Grandparents Raising Grandchildren Advisory Council during a six-month process with input from family caregivers, those they support and over 150 stakeholder organizations across the country. It marks the first time that multiple government agencies have worked together with the private sector to address the needs of family caregivers.

The plan is centered around five main goals: increasing awareness and outreach, building partnerships and engagement with family caregivers, strengthening services and supports, ensuring financial and workplace security and enhancing data, research and evidence-based practices.

“Family caregivers play a vital role in supporting people with disabilities and older adults so they can live and thrive in their own homes and communities, and it is time that we take action to champion them,” said Melanie Fontes Rainer, director of the HHS Office for Civil Rights. “The National Strategy to Support Family Caregivers is a concrete step toward making the right to community living a reality for all people, in keeping with federal law and the Supreme Court’s Olmstead decision.”

The national strategy will be up for public comment for 60 days starting Oct. 1. Going forward, it will be updated every two years.



10 TIPS FOR FAMILY CAREGIVERS



Seek support from other caregivers. You are not alone!



Take care of your own health so that you can be strong enough to take care of your loved one.



Accept offers of help and suggest specific things people can do to help you.



Learn how to communicate effectively with doctors.

1

2

3

4



Be open to new technologies that can help you care for your loved one.



Watch out for signs of depression and don't delay getting professional help when you need it.



Caregiving is hard work so take respite breaks often.

7

6

5



Organize medical information so it's up to date and easy to find.



Make sure legal documents are in order.



Give yourself credit for doing the best you can in one of the toughest jobs there is!

8

9

10



CaregiverAction.org

Take Care of Care Givers

November is the month where we take time to recognize and give praise and support to the 78 million people who dedicate their time, often unpaid, caring for a family member in need.

Particularly as we approach the festive season when focus is placed on family and quality time, it is important that we show our appreciation for those who work tirelessly to provide care; whether it be financial, medical, domestic or emotional support. We must never underestimate the strength that caregivers have for providing this support to those people who need it the most, nor the toll that it can take both emotionally and physically upon them.

The devotion and love that these people show to their loved ones therefore quite rightly ought to be celebrated. A Presidential Proclamation declaring November as National Family Caregivers Month provides much recognition for these devoted family members and acts as a backdrop for many national and local organizations to structure events, raise funds, provide support networks and most of all celebrate these wonderful people.

Every year a theme is chosen to focus awareness raising and information dissemination. Perhaps you know someone or are yourself who cares for a family member and would benefit from engaging with the activity taking place throughout November.

November is
NATIONAL FAMILY
CAREGIVERS MONTH

#CaregiverAnd

From Norman's Desk

Readers of my monthly column should know by now that I'm also interested in politics, and especially the intersection of politics, disability, and the resulting public policies that impact on people with disabilities.



The interest stems from being trained as a journalist during the Carter-Ford presidential campaign on a college campus with many activists with disabilities. A caught the "inside politics" fever.

And, by happenstance, I became involved with two political campaigns upon returning to New Jersey. One for a Republican and one for a Democrat, and I quickly learned that disability-related policies are not partisan issues at the local level.

This is why I encourage anybody with a disability to get involved with politics. First and foremost as voters. Then, if you like a candidate, become involved by volunteering with the campaign. Become engaged, ask questions, and don't just focus on disability issues.

We live in the Community. We need ask about issues beyond our own because our needs for safe neighborhoods, effective and efficient local governments, well maintained infrastructure, and well-run services are just as great as our able-bodied neighbors.

As messy and raucous as ours has become, I'm still a great believer in democracy. What is happening now, however, is not that unusual if you delve into early U.S. history. If Twitter had existed, Thomas Jefferson and Alexander Hamilton would have used Twitter to insult and degrade each other in their campaigns. They used the printing press instead

Our democracy is cheapened by the ugly discourse, but it is endangered much more by people opting not to peacefully participate in the process. Sure, there are winners and losers with participatory politics and elections, and, sure, democracies sometime make huge mistakes with major consequences. The key to democracy is not to stay engaged no matter who wins or loses.

A year from now we may be in the most contentious presidential campaign in my experience. In the next 12 months, I intend to bring you fact-based information on where presidential candidates stand on disability-specific issues. For example, I can report right now that of the 10 top Democratic presidential candidates, only Sen. Kamala Harris has specific policies targeted toward people with disabilities.

This may have changed by the time you read this, and if so, I will report that next month. If other candidate start generating disability-specific policies, it will be as a result of people with disabilities becoming engaged.

So, let's get engaged!

Norman A. Smith, Associate Executive Director -
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Feds Send Millions To States To Phase Out Subminimum Wage Employment

Reprinted from Disability Scoop by Shaun Heasley | October 3, 2022

Federal officials are sending \$177 million to states in a major push to shift people with disabilities away from subminimum wage work in favor of competitive integrated employment.

The funding will go to 14 state vocational rehabilitation agencies over the next five years as part of what's known as the Subminimum Wage to Competitive Integrated Employment demonstration project.

"These grants will support innovative efforts underway across the country to provide educational opportunities to youth and adults with disabilities so they can secure better-paying jobs, build economic security, and lead more fulfilling, independent lives," said U.S. Secretary of Education Miguel Cardona whose agency includes the Rehabilitation Services Administration, which is doling out the funds.

The pilot program was established in a government spending bill for the 2021 fiscal year. Projects funded through the effort are aimed at decreasing the use of subminimum wage and increasing access to competitive integrated employment.

With the grants, state vocational rehabilitation agencies will focus on using novel approaches to link people with disabilities to green jobs and opportunities in essential worker industries, the transportation industry and the arts where they will work alongside their peers without disabilities for comparable wages, the Department of Education said.

The projects will feature collaboration between state and local providers, public and private employers and advocates, officials said.

Currently, under a law dating back to the 1930s, employers can obtain special certificates from the Department of Labor allowing them to pay workers with disabilities less than the federal minimum wage of \$7.25 per hour. But, the practice known as subminimum wage, is increasingly falling out of favor with several states and cities phasing it out and some federal lawmakers seeking to do the same nationwide.

"Far too many people with disabilities would like to work but are living in poverty because they have not had the opportunity to find a career in a competitive integrated employment," said Rep. Bobby Scott, D-Va., who chairs the House Committee on Education and Labor and has introduced legislation to eliminate subminimum wage. "This historic investment in support of innovative activities aimed at increasing competitive integrated employment will help ensure that people with disabilities have meaningful opportunities not only to work but to thrive in their communities."

Grants from the new program will go to vocational rehabilitation agencies in California, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Minnesota, New York, North Carolina, Ohio, Pennsylvania, Texas and Virginia.

Paintings Made During Lengthy Hospital Stay Bring Teen With Autism New Audience

by Jason Laughlin, reprinted from The Philadelphia Inquirer/TNS | October 12, 2022

PHILADELPHIA — A year ago, painting watercolors was just another way to give a Bucks County boy with autism periods of peace during a long, difficult hospitalization.

Now, Emmett Tolis' paintings, which depict ordinary things like a slice of pizza, the Flyers logo, or a sausage on a fork, are attracting a wider audience, with some decorating cards that sell to customers as far away as Tennessee and Missouri, and more than 50 of them on display at the entrance of a Doylestown arts shop. Sales of the cards online and at local markets have brought in about \$10,000 over the last year.

For George and Elizabeth Tolis, of Jamison, the paintings offer a unique view into the mind of a 13-year-old son whose verbal expression is limited. "This is literally like seeing into Emmett's soul right here," Elizabeth Tolis said.

Some customers buy the cards without knowing anything about Emmett's autism, attracted by their innocence and bright, primary colors, said Robert Dorfman, a family friend who produces and sells the cards at his Warrington advertising and print shop, Peregrine Associates. Others are moved to buy after learning Emmett's story. "It's letting other people know Emmett's out there," said Dorfman, "and you're not alone in the world when you have someone with that type of autism."

Emmett started painting last year, while living at Children's Hospital of Philadelphia from July to November 2021. There were few other options for him while his parents struggled to find specialized care for his severe form of autism. Emmett experienced outbursts if his routine was disrupted, and his parents' bodies bore scratches from their efforts to subdue him. At the hospital, Emmett regularly had to be restrained.

Painting had never been part of Emmett's routine, his mother said, but she quickly learned that it offered a distraction and an outlet during the long months spent in a hospital room. "It was cheap, it was time consuming, and he was calm when he would do it," his mother said.

The paintings are either free form or start with sketches his mother makes of subjects that Emmett requests. In addition to everyday objects, Emmett enjoys painting other things that interest him, such as international flags.

At CHOP, Emmett's paintings wallpapered his otherwise bland hospital room.

Painting continued to be one of Emmett's favorite pastimes after he returned home. He often wears headphones while he works, his love of repetition satiated by listening on repeat to Kari Jobe's *The Blessing*, a Christian song.

Last year, his mother printed 150 Christmas cards for family and friends decorated with Emmett's holiday themed art. They were so popular, she said, she created a website with Dorfman to show and sell the art, and started offering cards at local farmers markets.

A plumbing business adopted Emmett's paintings of a toilet (he is fascinated by bathrooms) for thank you notes given to customers.

Emmett only paints subjects that interest him, Tolis said. A surgical center tried to commission thank-you cards featuring a heart for \$1,000, but Emmett refused to paint it. "He's a temperamental artist," she joked.

Emmett's paintings, including some he did during his extended hospital stay, were on display at the Mercantile at Doylestown, an arts shop and display space from September through mid-October.

The work was a good fit, said Brooke Henningsen, who founded the Mercantile during the pandemic to showcase and sell local artists' work. She felt it was important for parents of children with autism who may struggle to express themselves to see Emmett's creativity.

"They do absorb and see, and it's just in their own way," she said.



Emmett Tolis with his parents, Elizabeth and George Tolis, at the Mercantile in Doylestown, Pa. where his paintings are on display. (Tom Gralish/The Philadelphia Inquirer/TNS)

The family wound up at CHOP for months last year because there aren't enough resources for children with behavioral and emotional disabilities, including a shortage of skilled workers who were qualified to care for Emmett.

A year later, it's still the norm for families to wait months for services. The pandemic exacerbated a scarcity of providers even as it worsened the struggles of children with autism.

"This could be a very critical moment in people's lives, and then they have to wait months and months," said Mark Davis, president of Pennsylvania Advocacy and Resources for Autism and Intellectual Disability.

Pennsylvania has 483 residential hospital beds for children with intellectual disabilities or autism, the state Department of Human Services reported, but they can't fill them all because there aren't enough staff to care for that many children. Others are reserved for children with specific disabilities. The state plans to launch next year a program to train more staff to work with children who have a dual diagnosis of an intellectual disability, autism and a mental illness.

Elizabeth and George Tolis were wary of bringing their son home from CHOP last year. The stay there, though, led to outpatient care from a hospital psychiatrist. Emmett was weaned off all the medications he had been prescribed, then introduced to a new drug regimen focused on preventing seizures and stabilizing his mood. His parents rearranged their schedules so one is always with Emmett.

The family has donated some money from the card sales, including to a local playground adapted for children with sensory difficulties. They hope to create a charity to support organizations that provide aid for families in crisis.

At this time last year, Emmett's parents were contemplating the possibility that they would not be able to keep Emmett at home. Today, they and Emmett's two older brothers are still in many ways shaped by the boy's needs, but he has become more flexible and his reactions to frustration less sudden.

"A year ago," George Tolis said. "the family was completely apart, and now we're not."

Disney Expands Costume Options For Children With Disabilities

by Shaun Heasley reprinted from Disability Scoop| October 18, 2022

Just in time for Halloween, Disney is adding to its lineup of costumes customized to meet the needs of kids with various disabilities.

The company said it is now offering eight adaptive costumes and five wheelchair covers, allowing children to dress as iconic characters like Jasmine from “Aladdin,” Woody or Buzz Lightyear from “Toy Story,” Elsa from “Frozen 2,” Black Panther and more.

The adaptive costumes feature stretch fabric that opens in the back to make them easier to get on and off as well as longer inseams for wheelchair-friendly wear and flap openings on the front to allow for tube access. Wheelchair covers are designed to fit standard 24-inch wheels.



Disney is increasing the number of options available in its collection of adaptive costumes. (Disney)

Disney first introduced its line of adaptive costumes in 2020. Naveen Seshadri, executive vice president of global retail at Disney, said that the success of the products has prompted the company to produce more.

“Disney’s adaptive roleplay line has been really well received by the community and popular among both children and adults,” Seshadri said. “As we expand the adaptive roleplay collection, we are able to connect our iconic franchises with fans and families with thoughtful design that meets the needs of more of our guests and allows everyone to take part in their favorite stories.”

Disney’s adaptive costumes and wheelchair covers are available on its website for \$49.99 each. In addition to Disney, Target offers a selection of adaptive costumes for kids too.

