August 2018

New Horizons

Housing That Supports Independence

Project Freedom INC

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New York Woman Is Nation's First Lobbyist With Down Syndrome

As the first registered Capitol Hill lobbyist with Down syndrome, Kayla McKeon speaks with powerful credibility when working to change laws that limit career opportunities for people with disabilities. "I like being able to share my story and my experience to members of the Senate and congressmen and women," McKeon said. "I like telling them about my abilities and how they can help us and pass these laws. It's hard for them to say no to a self-advocate."

McKeon, 30, who works for the National Down Syndrome Society, has already helped achieve passage of the ABLE to Work Act, which allows employees with disabilities to save more money without losing their Medicaid or Social Security benefits. She's now working to eliminate subminimum wage, which pays workers with disabilities as little as pennies per hour. "Down syndrome doesn't hold us back, it's old, antiquated laws that do," McKeon said. "We also want the same pay and benefits as everyone else because we are like everyone."

In October, McKeon began working part-time at the nonprofit, where 25 percent of employees have Down syndrome. She lives with her parents in Syracuse, N.Y. and flies to Washington or New York City several times a month. She has met with elected officials ranging from U.S. House Speaker Paul Ryan, R-Wis., to Sen. Tammy Duckworth, D-Ill. The hardest part of her job is getting on the calendars of busy lawmakers who may need to reschedule if they are called to the floor, McKeon said. "I am nonpartisan and bipartisan," McKeon said.

Sara Hart Weir, president and CEO of the National Down Syndrome Society, said McKeon's position was created as part of a strategic process to hire more people with Down syndrome. Weir said McKeon has a passion for advocacy and exemplifies achievement.

McKeon's work has been noticed by others advocating on behalf of people with disabilities. Stuart Spielman, senior policy advisor and counsel for Autism Speaks, said McKeon is positive and well prepared as she weaves together policy with personal experience. "It has been wonderful getting to work with Kayla," Spielman said. "She is an asset to NDSS and a great advocate for people with intellectual and developmental disabilities on Capitol Hill. We are lucky to have the opportunity to work alongside her."

McKeon's mother, Patti McKeon, said her daughter is well suited to her role because of her social graces and ability to talk to anyone without feeling nervous.

"We can do anything that we set our minds to," McKeon said. "We go to college, we drive a car, we can pursue relationships. We can work. Let us be who we are."

by Courtney Perkes | Reprinted from June 26, 2018 DisAbilityScoop

A Publication of Project Freedom Inc. / Robbinsville, Hamilton, Lawrence, Woodstown, Hopewell, Toms River & Westampton
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"My Two Cents"

By *Tim Doherty, Executive Director*

" What goes around, comes around." " What once was old is now new." I am sure we have all heard theses phrases before, so you won't be surprised when I tell you that I am referring to issues revolving around Affordable Housing in New Jersey.

Yesterday I attended an open hearing of the Assembly Committee on Housing. The committee members were called together by chairman Benjie Wimberly (D. Passaic) to discuss the state of affordable housing and the complaints of several Towns about the burden that affordable housing will place on their towns. This is the result of COAH not passing third round rules back in 2015, so the Towns have had to go to the Courts to resolve these issues. Most have settled with Fair Share Housing and have had their affordable housing plans approved by the Courts, however with numbers that they still don't like. And so, a call for a return of COAH to administer these plans and settle these issues.

That would be all well and good, if COAH had been allowed to work as it originally was set up. In the early days, the COAH board was a bi-partisan Board and would work with towns to discuss their affordable housing issues and ultimately arrive at a settlement. However, the towns still railed against having to do their housing obligations, so then governor Christi' sought to marginalize COAH to the point that it was no longer able to function. Ultimately, The Supreme Court ruled that until COAH is re-constituted, Towns would have to have their housing plans certified by the courts. So that is where we are today.

Settling through the Courts was always an option, however today it is the place of last resort, so that Towns now must finally settle, establish their plans and then help to get the construction done. This is what they don't like. At yesterday's hearing, I heard a lot of statements from the members of the committee, as well as from the mayors of many towns, of how they support affordable housing however they are worried that they don't have sufficient infrastructure within their towns, to manage this new growth. They fear overbuilding of the town, overcrowding in their schools, and higher taxes. All this really without having any new construction being built yet.

So, this clearly is still a very big issue for towns in New Jersey. We are yet to hear about the new Governor's position on Affordable Housing. Will the Governor re-institute COAH or a like body that will take up these issues and remove them from the courts. Or will he allow the process to run its course, through the judicial system, ultimately having judges making the decisions as a Town's affordable housing plans.

My experience has been that even when COAH was an active body, some towns would still delay, and throw up barriers as to why they couldn't comply with the law. However, with the issues in the hands of the courts, Towns have been forced to settle and move on. My recommendation would be to stay the course, allow the Courts to do their job, and settle these issues. No longer are towns allowed to get away with delay after delay, hoping for some governor or new legislature to change the law. Given some time, we will begin to see new housing develop that will ease the burden of those who need it. Finding decent and affordable housing should be something that we should all support.

From Norman's Desk

This year will be the 23rd time in my life that I cast a vote for a member of Congress. I remember back in 1972 being forced to vote two weeks ahead of time by absentee ballot because my polling place was not accessible. I remember in 1992 being challenged at the poll because of disability, and I remember the empowerment I felt by calling a state hotline while at the poll to "fix" the situation to my satisfaction.

Times have changed for people with disabilities in terms of voting ease. Now most polling places and polling booths are accessible. Voting early by mail is encouraged for everyone in many states. Yes, there are still barriers to voting—especially in other states, but there is no excuse for any person with a disability not to vote. Nothing about us without us, right?

But I want to talk about something besides voting. I want to talk about people with disabilities getting involved with political campaigns. I have done it twice when I first starting out. I worked on a statewide Republican campaign for governor and a county campaign for a Democrat. They both lost, and that may be a commentary of the type of person I support.

Nevertheless, these campaigns opened doors for me, and, more importantly, these candidates, their staffers and supporters gained a greater understanding of my needs as a person with a disability. This was a great asset in advocating on disability issues through these same people over the years.

"Nothing about us without us" can take many forms at all levels of government. But we need to be involved to make this come true! We need to be involved from the start by voting! Before we go to public meetings, before we demonstrate, before we sit-in, before we get arrested, WE NEED TO VOTE!!! The rest is meaningless unless we exercise our right to vote.

To paraphrase our great leader Justin Dart: We need to vote as if our lives dependent on it! We all need to vote on November 6!

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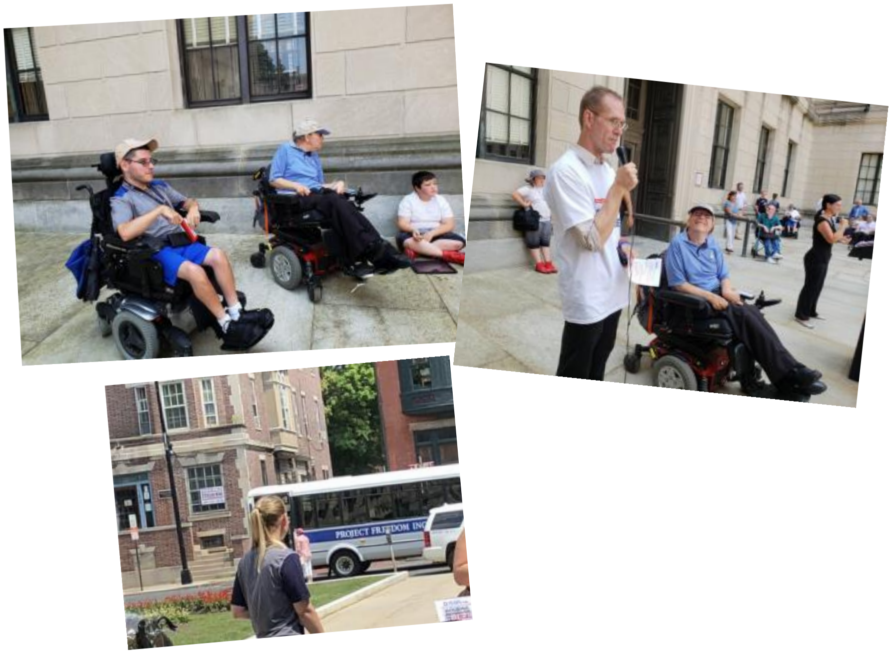

‘Wrap-Around’ Model Helps Prevent Behavioral Hospitalizations

by Scott Scanlon, Reprinted from The Buffalo News/TNS | July 24, 2018

BUFFALO, N.Y. — Erie County Medical Center had the distinction last year of releasing a teen patient with severe autism from the behavioral health emergency room — after 304 days.

The 16-year-old was one of hundreds with developmental disabilities in the region — and thousands across the nation — who fall into a gray area each year. Where to best help them when an explosive outburst requires emergency care: in a mental health or more typical hospital setting?
“You can treat them and get them out but still, a lot of families at that point are beyond being able to handle things anymore,” said Dr. Michael Cummings, associate medical director in charge of the ECMC Regional Center of Excellence for Behavioral Health. “You can’t imagine how hard it is to acknowledge to yourself that leaving a child in an emergency room is better than taking them home.”

The hospital, New York State and a quartet of regional nonprofit foundations believe they have found an answer for most parents, and patients, in such shoes — the Access to Psychiatry through Intermediate Care (APIC) program, a team that makes house calls to challenged families in 17 upstate counties.
Cummings and Janell Van Cleve established APIC in late 2014. They lead a staff of six, split into pairs, which sit down with families in crisis, connect them with key medical and social services, and develop strategies to prevent avoidable emergency room and hospital stays.

The program is free for those of any age — and their loved ones. It focuses on four key areas: medical needs, alternative behavioral health therapies, creating a better home environment, and trying to free up caregivers for much needed breaks. **“If you take a mom with severely autistic child and measure her stress levels, she measures identical to an active duty combat veteran in Afghanistan,” said Cummings.**
He and Van Cleve said Erie County Medicaid data shows the program has helped foster a 40 percent reduction in hospitalizations, 30 percent reduction in ER visits, and 50 percent increase in outpatient case management visits during the last 3½ years among the population it serves. They said they’ve also seen a 40 percent drop in family reported aggression measures and a 50 percent drop in family distress.

Q: What is the wrap-around model?
Cummings: In the medical model, it would be something like, “You’re in a wheelchair now. Medicaid can spend a huge amount of money having you live in an assisted living setting, or a very little amount of money building a ramp so you can get in and out of your existing home …
In behavioral health, it became more about “this kid needs a peer, needs rise-and-shine help — an individual that comes into the house and helps get your kid up and on the bus.” It sounds silly to parents who don’t have problems getting their kids up and on the bus, but if you have a behaviorally health-challenged child and they don’t get on the bus, then they don’t go to school. Then you can’t go to work, and after a while they get kicked out of school.
Van Cleve: Then you have Child Protective Services on your back.
Cummings: So you’re paying an aide to come help a parent — for a short term. Originally, wrap-around worked really well because it kept kids out (of inpatient behavioral centers). That can cost $120,000 per kid, per year, and wrap-around costs about $20,000. So you could serve five or six families for every one kid you kept out of placement.

Q: What is the criteria?
Cummings: You need to have some form of developmental disability. It can be an intellectual disability. It could be autism, a severe learning disorder, Down syndrome, fetal alcohol syndrome. You also need to be at risk for system penetration that’s avoidable. For us, that’s inappropriate hospitalizations, inappropriate ER visits, over-medication, risk of arrest or loss of school placement.
Van Cleve: It also could be a suspected disability. We get a lot of folks who call and say a child has an alternative track for learning, and think there’s something else going on but we haven’t gotten through all the testing, and nobody’s really sure. If there’s suspicion, we will entertain the case because we want these folks to get help sooner. We can identify what’s going on and how they need to be treated.

Continued on pg 10

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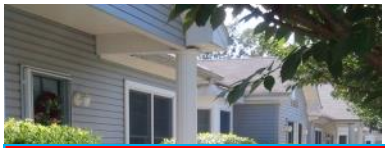
Lawrence Events

DATE	DAY	PROGRAM (in Community Room)	TIME
1-Aug	Wed	Massages	Sign up
3-Aug	Fri	Hamilton/Lawrence Shopping	Bus Leaves PFR 9:30 AM
8-Aug	Wed	Nutrition	7 PM
9-Aug	Thu	Lawrence Salad Making	3:00 -5:00 PM
15– Aug	Wed	Movie Day	2:30 PM
16-Aug	Thu	Lawrence Games	2:00 PM-4:30 PM
21-Aug	Tue	Keep Calm & Color On	3-4:30 PM
28-Aug	Tue	Lawrence Snow Cones Making	2:00 PM-4:00 PM



Hamilton Happenings

DATE	DAY	PROGRAM (in Community Room)	TIME
2-Aug	Thu	Hamilton Christmas Games	2 PM-4 PM
3-Aug	Fri	Hamilton/Lawrence Shopping	Bus Leaves PFR 9:30 AM
6-Aug	Mon	Day Program	2 PM-4 PM
10-Aug	Fri	Hamilton Salad Making	3:00 -5:00 PM
13-Aug	Mon	Day Program	2 PM-4 PM
20-Aug	Mon	Day Program	2 PM-4 PM
21-Aug	Tue	Hamilton Snow Cones Making	5:00 -7:00 PM
27-Aug	Mon	Day Program	2 PM-4 PM
31-Aug	Fri	Hamilton Tropical Games	2:00 PM-4:00 PM

Robbinsville Events

DATE	DAY	PROGRAM (in Community Room)	TIME
7-Aug	Tue	Robbinsville Salad Making	5:30 -7:00 PM
24-Aug	Fri	Robbinsville Snow Cones Making	1:30 -3:00 PM
30-Aug	Thu	Robbinsville Games	2:00 PM-4:00 PM

Hopewell Events

DATE	DAY	PROGRAM (in Community Room)	TIME
1-Aug	Wed	Heart to Hearts Chair Message	1:15 pm to 3:15 pm
10-Aug	Fri	Mercer Home Health Hosting Pokeno	3:00 pm
24-Aug	Fri	Heart to Hearts Chair Message	11:30 am to 1:30 pm
28-Aug	Tue	The Senior Store Hosting a Medicare Bingo and	3:30 pm

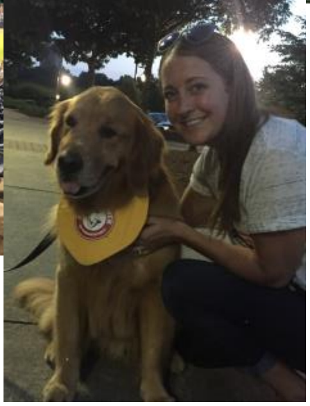

Held July 13th with lots of food, drink, italian ice, inflatables, sand art and spin art for the kids.

Toms River Luau Party

July 26
Trenton Thunder Picnic

HOMETOWN HERO FAN OF THE GAME AWARD GOES TO TIM...

WHO KNEW!



Continued from pg 5

Q: Do these cases take place in every community across the region?

Cummings: We are everywhere from the roughest neighborhoods in the region we cover to the most wealthy suburbs, and everywhere in between. Many of these families already are dealing with OPWDD, Office of Mental Health, the educational system, possibly the Department of Social Services, juvenile justice systems. We're experts at this and it's hard to navigate, so families in general — regardless of education, regardless of socioeconomic status — to navigate through this system with different acronyms, different structures, is almost impossible.

We do more high-level air traffic controlling than psychiatric stuff. We installed locks and alarms at one kid's house so he can't get out while his mother sleeps — and she can get sleep without worry of being charged with child neglect. The kid does not need a prescription or a hospitalization. He needs alarms. They cost $200, where the prescription costs $1,800 a month. If you look at all of our cases and divide by our budget, we spend on average about $2,000 per case.

One day in CPEP (ECMC's Comprehensive Psychiatric Emergency Program) is about $1,900. An inpatient stay is about $1,200 a day. Forget about the cost of jail, ambulance rides, which are harder to measure. If we can avoid one of those, it almost covers our costs. There are only a few inpatient units nationally for severely developmentally disabled kids in crisis (and in need of longer-term care). The place that gets used most for New York State kids is a place down in Johns Hopkins in Baltimore called the Kennedy Krieger Institute. That costs New York State, on average, about $1.4 million per kid, per year. If we prevent one kid from going, we've saved New York State more than double our operating budget.

Q: How does a house call work?

Cummings: We walk into a household and start on common ground. When you let the family tell their story, you get 90 percent of the information you were going to get anyway, just not in the order you were going to ask it. Then there will be some basic things you'll fill in. Then we work with the family and ask, "What are the three to five things we can do to make your life better?"

It's hard for families. They start with the child or identified patient, and there's a lot of stuff to do there, but we need to get to the whole family. What do you need as parents? What do the siblings need that they're not getting? These siblings don't have birthday parties. No one comes to the house. They don't have sleepovers. There are literally kids that go home and deadbolt themselves into their room because it's the only way they're safe. It's an entirely different existence.

We look at where we can get the most gain, do things for families that others might laugh at, like respite funds to pay a family member. We've done everything from dinner and a movie to sending families (for a night away). The family gets to be human again. Mom and Dad get to take a deep breath. It's really instilling hope

August 1
Martin Battisti

August 12
Lorraine Schreiber

August 17
Dawn Watkins

August 19
Cindy Arkuszewski

August 21
Chardornay Brown

August 24
Cecilia Funk

August 25
DeManuel Edmondson

August 26
Rein Kukk
Renea Whitaker

August 30
Cynthia Hill

August General Recreation

Club Freedom Events Highlighted

4-Aug	Sat	Aquatics Hamilton YMCA	Bus Leaves PFR 11:30 AM
8-Aug	Wed	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
9-Aug	Thu	Shore Trip - Seaside 5 People Needed	Bus Leaves PFI 9:30 AM
15-Aug	Wed	Dine Out - Dinner - Red Robin	Bus Leaves PFR 4:30 PM
16-Aug	Thu	Columbus Farmers & Flea Market	Bus Leaves PFR 9:30 AM
18-Aug	Sat	Trenton Thunder Baseball Game	Bus Leaves PFR 5:00 PM
22-Aug	Wed	Atlantic City Air Show 5 People Needed	Bus Leaves PFI 9:00 AM
25-Aug	Sat	Aquatics Hamilton YMCA	Bus Leaves PFR 11:30 AM
29-Aug	Wed	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
1-Sept	Sat	Trenton Thunder Last Game	Bus leaves PFR 5 PM

Lakewood Renaissance Faire

$10 for Club Freedom Members only

Saturday Sept 15, 2018

Bus leaves Robbinsville 9 am sharp
($7 per person admission / $3 transportation)
NO REFUNDS
Bring extra money for lunch, etc.
First paid will have a seat on bus–
no reservation without payment!

18th Annual Project Freedom Labor Day Picnic at Robbinsville

MONDAY SEPT 3rd
11:30 –1:30 pm

All are welcome as we gather around the campfire for a summer picnic with all your favorite camp foods

Please wear your favorite plaid flannel shirt or hat

Contact Mary or Esther by Aug 24th—609-448-2998

Project Freedom Inc.
223 Hutchinson Road
Robbinsville, NJ 08691

Project Freedom Inc. is a 501 (c)(3) not for profit organization dedicated to developing, supporting and advocating opportunities for independent living for people with disabilities

Slow Cooker Corn on the Cob

Coat corn on the cob with a flavorful compound butter and pop in the slow cooker for a fuss-free summer dinner side dish.

MAKES: 8 SERVINGS
SERVING SIZE: 1 EAR + 1 TABLESPOON BUTTER
MAKES: 8 EARS OF CORN + 1/2 CUP EACH BUTTER
PREP: 35 MINS
SLOW COOK: 4 HRS LOW OR 2 HOURS HIGH

DIRECTIONS

Place 1 ear of corn in a square sheet of foil. Top with 1 1/2 teaspoons of butter. Wrap corn and place in a 6-qt oval slow cooker. Repeat with remaining corn.
Cook on LOW 4 hours or HIGH 2 hours. Serve with additional Compound Butter, if desired.

FROM THE TEST KITCHEN

If using multiple compound butters, you can label the foil before cooking so everyone can get theirs back!

COMPOUND BUTTERS* (MAKES ABOUT 1/2 CUP)

Herbed: 1 stick butter, softened + 1 tablespoon desired herb + 1 teaspoon lemon juice + teaspoon ground black pepper + 1/8 teaspoon garlic powder
Cowboy: 1 stick butter, softened + 1/4 cup crumbled bacon + teaspoon ground black pepper
Elote: 1 stick butter, softened + 1 tablespoon snipped fresh cilantro + 1 tablespoon grated parmesan cheese + 1 to 2 teaspoons chile powder + 1 teaspoon lime juice
Fruity: 1 stick butter, softened + 2 tablespoons desired flavor freeze-dried fruit

Reprinted from https://www.bhg.com/recipe/slow-cooker-corn-on-the-cob/