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NEWS

'Stop the Shock': FDA Director's Home Besieged by Disability Rights Activists

by John Zangas | Published March 22, 2018

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Washington, DC — Disability rights activists have for the last two weeks made a tiny, nondescript park at 24th and I Streets NW into a temporary base of operations. "ADAPT Freedom Park," as they've christened it, is nothing but a triangular sliver of grass bordered by tulip bulbs. Blankets, sleeping bags and inflated mattresses sprawl on the grass, and aluminum containers full of black beans, barbecue chicken, mashed potatoes and veggie casserole are neatly stacked on two park benches. Cookies, doughnuts, coffee and snacks pile up around them.



The ADAPT occupation has weathered wind, snow, ice and freezing temperatures highly unusual for March./Photo by John Zangas

Banners, painted in black block letters, are what declare [the park under occupation](#) and the building across the street under siege. "Stop the Torture!" they say. "Director of FDA: Release the Regulations."

The activists, from various chapters of the disability rights advocacy group [ADAPT](#), have traveled from around the country to be here. A hardcore team of seasoned leaders, they fight for civil rights for disabled people. They are determined to do what it takes to convince the current FDA Commissioner, Dr. Scott Gottlieb, that abuse of their disabled and autistic "brothers and sisters" by aversive electric shock therapy will come with heavy political consequences. They have chosen the park outside his condominium to make their stand.

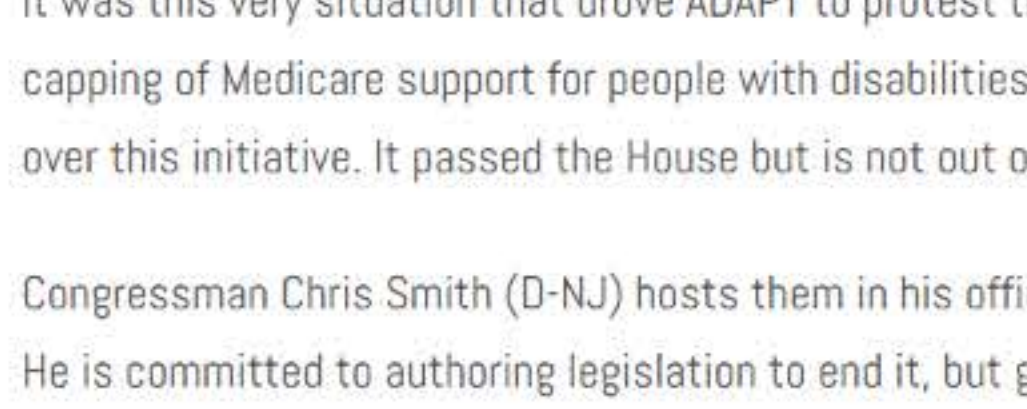
They plan to stay there indefinitely, until he meets with them to hear their demand: sign the order to end the electric shock of disabled persons at Judge Rotenberg Center (JRC) in Canton, Massachusetts.

They have been in the park 12 days. Nobody thought they would be there this long or realized how much of a toll it would take on their bodies. The days pass slowly as they work, plan and wait for a response from the FDA. With each hour they grow closer and more committed to fighting for the rights of students at the JRC facility. Their costs are going up too, with the account funds dwindling, they must call in for financial help. They've put everything on the line for their sustained protest. This is their "Standing Rock" moment, they say.

Day 7, Thursday, March 15, Legislative Day of Action on Capitol Hill

Transporting a large group on motorized wheelchairs via Metro is no easy matter. One must pass through two elevators—one elevator to descend to the pay kiosks and another to access trains. The lifts are also narrow and barely fit two motorized chair vehicles. A special kiosk for motorized chairs works slowly. The elevator design is inherently ableist, remarked Priya Penner, an ADAPT National disability rights activist, when explaining the challenges of what should be a short trip to Capitol Hill from ADAPT Park.

What would Metro be like if it were designed with access for the disabled equal in priority with others? From her perspective, Penner sees some easy fixes: one elevator to descend to the platforms and payment made by a barcode or better yet, made online.



This is the essence of daily life faced by physically disabled persons in most everything they encounter. Combine that with crumbling infrastructure, cracked sidewalks and difficulty accessing many older buildings, and it becomes clear that despite progress, there is still a long way to go for the disabled to reach equality of access with others.

Transit from the park to Capitol Hill is challenging enough for 15 people in wheelchairs, but the real roadblock facing them is getting support for passage of legislation banning aversive electric shock. Even if a regulation is in place, a subsequent administration could gut it later. This is why

such permanent legislation is needed, say the activists.

It was this very situation that drove ADAPT to protest the healthcare bill in June of last year, which is essentially a capping of Medicare support for people with disabilities. Dozens were [arrested](#) at Congressman Mitch McConnell's office over this initiative. It passed the House but is not out of committee in the Senate.

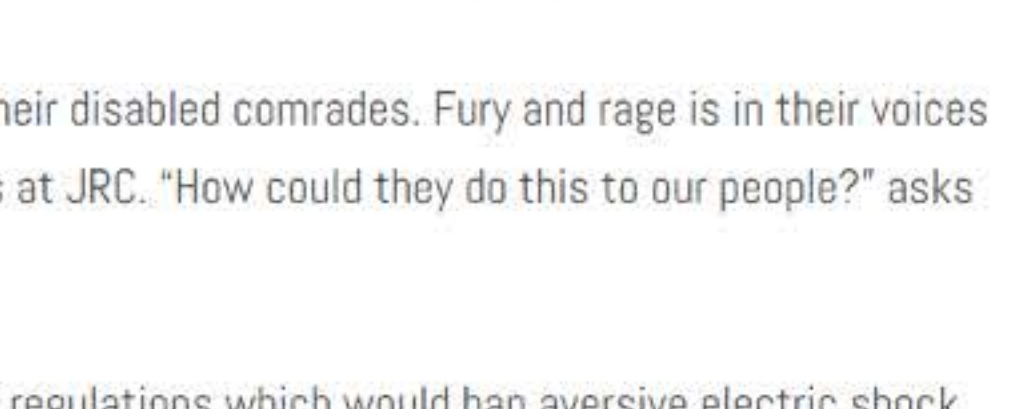
Congressman Chris Smith (D-N.J.) hosts them in his office and hears their request to end aversive electric shock therapy. He is committed to authoring legislation to end it, but getting such legislation written and passed will take time. And with the present administration working to gut disability rights already afforded under the Americans with Disabilities Act of 1995, it is doubtful such legislation would even make it to a vote on the House floor. Still, they persist. Their presence in his office at Rayburn House Office Building is a powerful statement in itself.

Day 8, Friday, March 16, ADAPT Park

On Friday night at 7:30 pm, as night falls and a cold stiff wind is pushing the activists to their physical limits, they form a circle for the nightly meeting. The last of rush hour traffic is dribbling back to the suburbs as they point their wheelchairs in toward the park center, meeting without using a bullhorn, and except for a few cars and buses, it's quiet enough so passers-by can't hear their plan of action for the next day. There is no hierarchy here.

The activists circle their motorized chairs, heading around Mike Oxford, a tall, grey-bearded man dressed in khaki overalls. The cold from the wind causes them to lean in to him while the warmth of his voice assures and captures their attention. He guides them like an oracle as they discuss the plan for the night watch and what they will do the next day. Oxford is trusted and regarded as a seasoned organizer. He scribbles his notes in a small book and avoids using his cell phone for contacts. He rarely opts to use the apps, defaulting instead to recording contacts in a little brown book. A few of the activists joke about how lost he would be if he misplaced his book. But they trust his experience and judgement.

Oxford reviews the line up of the shifts and reads aloud the names of who is to replace who on the next watch. At night they must keep careful watch, since anyone can come by and remove equipment or personal items. The park is a dangerous place. A minivan was broken into the night before while the activists were nearby, but no one heard the glass break or was even aware it happened until the owner asked if they heard it.



Air mattresses and blankets are spread on the park grass./Photo by Anne Meador

Many of the activists have left jobs and their warm homes to be in this cold weather prone park to protest on behalf of the rights of the JRC students they have never met. Oxford admits that he's not even sure the students at JRC know the activists are fighting for their rights. And as their protest goes into its second week, they didn't expect it to last this long. Now they can't go back. They refuse to quit, no matter what the weather does in the coming days. Tuesday night's weather forecast is calling for a snow storm, and a few inches of snow and rain, the harshest conditions yet, but they plan to be here no matter what.

They have a willingness to do whatever it takes to be there for their disabled comrades. Fury and rage is in their voices when they speak of the electric shocks inflicted on the students at JRC. "How could they do this to our people?" asks Penner.

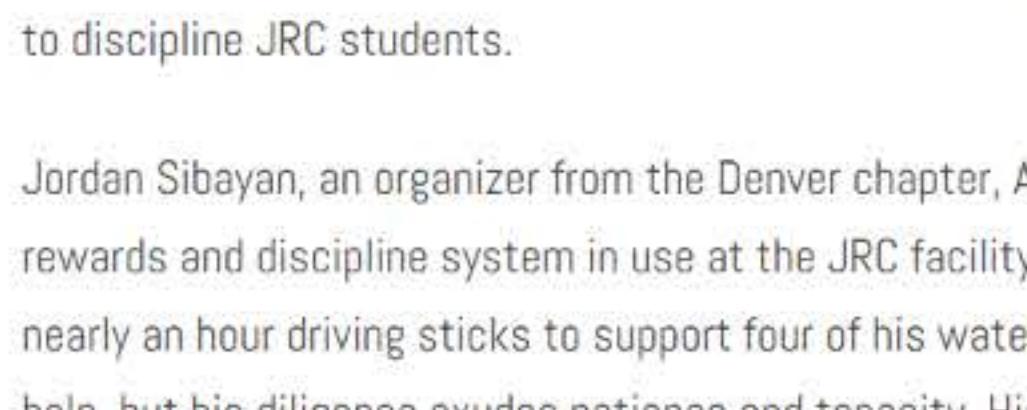
FDA Commissioner Dr. Scott Gottlieb holds the power to end the regulations which would ban aversive electric shock therapy, and he could do it with one signature. It is all but certain that their encampment can be seen from his second floor condominium in the modern building overlooking ADAPT Freedom Park. And if he isn't looking out his window, he can hear their periodic chanting and drum rounds.

By far the biggest enemy they confront is the cold. It takes a toll on the motorized wheelchair batteries by limiting the charge, and drains the activists' energy. It's evident they are truly suffering from it. Despite being swaddled from head to toe with hats, scarves, blankets and uncoupled layers of clothing and using hand warmers, their limitations of personal physical immobility allows the cold to penetrate their bodies. And it is painful. Several rock back and forth in their chairs to push out the cold. They struggle to stay warm and keep spirits high by listening to music and talking and joking among themselves. Whether or not their occupation fails or succeeds, they will be cold-hardened warriors when it is over.

Day 9, Saturday, March 17, 5 PM, St. Patrick's Day

Tony sits on the grass making a poster board sign with a black Sharpie: "Stop the Torture, Free the Students." He draws a large four-leaf clover in the corner using the same black Sharpie. He muses that it is black because it is a liberation shamrock.

A cold drizzle has begun to fall and several retreat under blue tarps attached to trees at the edge of the park. Priya Penner calls over to Tony and asks him when he is giving her raincoat back. "When I'm done using it," he says, laughing. She isn't even bothered by his laughter but could have been. Tony is too happy-go-lucky for anyone to get mad at him for doing anything they don't like. She shrugs, as if she expects Tony to keep it the raincoat until it stops raining.



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The drizzle falls harder and begins to wash away the chalk banner, "Welcome to ADAPT Park." Some of the signs begin to sag while other chalk messages disappear altogether.

There is a carton of thick chalk sticks under a bench. Someone will color the "Welcome To ADAPT Park" message once the rain stops and the sidewalk dries.

What the activists need and want won't come in the form of signs, hand warmers, blankets or tarps. It will come in the form of freedom and liberation from the fear of abuse their comrades face at JRC.

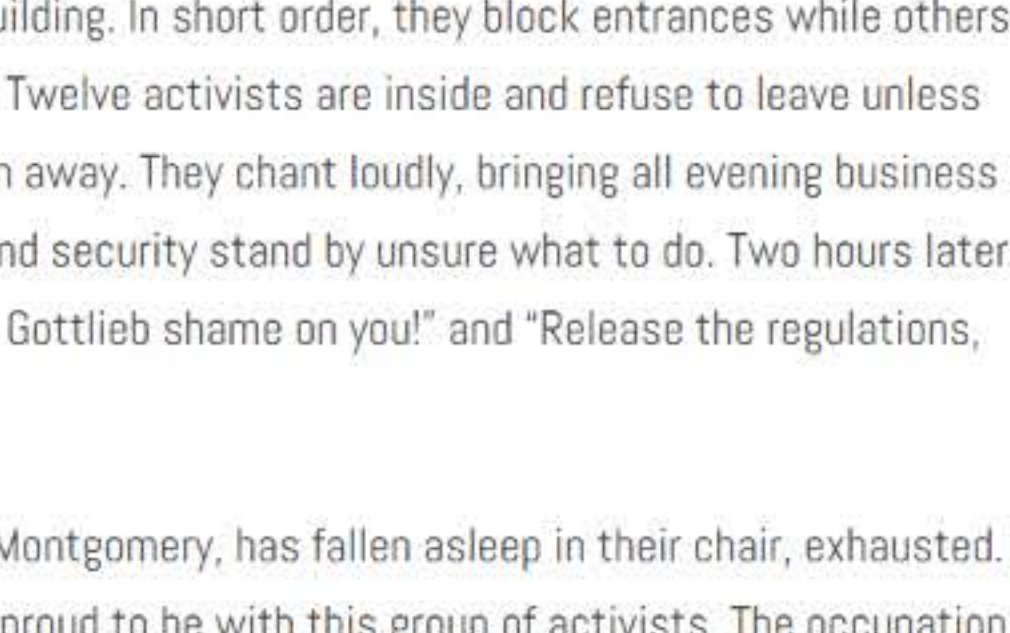
Late that night after the rain has ended and a cold wind sweeps the park, the activists gather in front of Dr. Gottlieb's condominium. They yell, "Stop the Shock, Stop the Torture!" while making noise with drums and air horns. A security guard comes out with a video camera to hush them up. But they persist. Police are called. It is 9:59 pm, and to avoid breaking a noise statute, they return back to the park across the street. Police arrive, but by then the activists have long returned to the park across the street. The police leave without approaching or speaking to them.

Day 10, Sunday, March 18, ADAPT Park Neighborhood Party

The activists decide to hold a party in the park and spread invitations for a barbecue to the neighborhood. On the menu are grilled hotdogs with a vegan option, potato chips, drinks and snacks. A few neighbors stop by and several activists explain why they are there. All the visitors react the same way, with stunned disbelief that electric shock is being used to discipline JRC students.

Jordan Sibayan, an organizer from the Denver chapter, Atlantis ADAPT, sets up his "Yellow Brick Road" of a rewards and discipline system in use at the JRC facility. He lowers himself from his chair onto the ground and labors nearly an hour driving sticks to support four of his watercolor drawings into the dry dirt of the tulip bed. He asks for no help, but his diligence exudes patience and tenacity. His fiancée, Jacqueline Mitchell, another activist he met at a past protest hand him the sticks and bricks collected to erect the signs. Jordan and Jacqueline plan to get married this year.

He encourages her to repeat a chant about the FDA, but she doesn't want to repeat it out loud. It has a bad word in it, she says. He keeps on asking her until she finally yells it out. Everyone laughs. Sibayan smiles because he got her to say it.



ADAPT activists hold a block party and barbecue to attract people to the park./Photo by Anne Meador

The wind keeps blowing down the signs but he persists in putting them back up. The drawings depict scenes of abuse at JRC. He uses them to explain to visitors the yellow brick road scheme of shock punishments in use at JRC. Most visitors are surprised to hear about it and listen intently to him.

All except one. A tall grey-haired man approaches the activists with an admonition about the nightly noise they make outside his condominium. He argues with two of the activists for a while, telling him how much of a disturbance they

All except one. A tall grey-haired man approaches the activists with an admonition about the nightly noise they make outside his condominium. He argues with two of the activists for a while, telling him how much of a disturbance they are. "How would you like to be shocked?" asks Colleen Flanagan, a disability rights activist from Boston. She hears his concerns about the noise, but he does not listen to her explanation and reasons for the protest. He leaves in frustration. Flanagan is upset by the man's response, but admits it is part of what ADAPT does to be on the cutting edge of the movement for disability rights. ADAPT has earned its achievements through pushing the boundaries of civil disobedience, she says.

Another visitor stops by, curious about the signs. Paige Bradford teaches students with disabilities and is working on her Ph.D. at George Washington University. She encourages the activists. She shows that all the research in aversive electric shock, also known as "positive punishment," evidences it only works when it is being used in an institution. Once the student is released from the facility and returns to the community, they go revert to the same behaviors. "Positive punishment does not extinguish behaviors," according to Bradford. The solution is to work with the students in finding ways to help them find ways to cope with stress, not to force them to behave in a certain way through punishment and fear.

She speaks about the fact that a [special report](#) on abuse and torture published by the UN has cited JRC as violating its convention. No one should be subjected to this, she says.

ADAPT will celebrate its 40th anniversary in Denver in June. The activists and organization takes credit for grassroots efforts to achieve many rights for the disabled, such as lifts on buses, improvements in building access, sidewalk access ramps and the Americans with Disabilities Act of 1995.



Day 12, Tuesday Night, 8:30 pm, March 20th, 2018 FDA Headquarters in Silver Spring

The activists travel en masse to Silver Spring for a civil disobedience direct action at the FDA headquarters building. In short order, they block entrances while others lay on the floor for a die-in. Twelve activists are inside and refuse to leave unless they are arrested and taken away. They chant loudly, bringing all evening business to a stop. Police respond and security stand by unsure what to do. Two hours later they are still chanting, "Dr. Gottlieb shame on you!" and "Release the regulations, end the torture!"

One of the protesters, Cal Montgomery, has fallen asleep in their chair, exhausted. Montgomery says they are proud to be with this group of activists. The occupation has given Montgomery a new purpose, one they had not experienced before.

The ADAPT activists continue chanting for three and a half hours in the FDA lobby. They live stream the action until midnight. Then they leave the office but block traffic in front of the FDA building on New Hampshire Ave. Police have had enough. They arrest eleven of them and ticket them for obstructing traffic. They are released at 3 am and return to DC, exhausted.

Montgomery reports that police sent a Metro bus equipped to pick them up because there are no accessible cabs in Montgomery County.

They arrive back in DC in the predawn hours. It has begun to snow. If the FDA was ignoring the activists, they must have finally taken notice now. They'll be back. The battle is just beginning.

ADAPT National organization is [raising funds](#) to support the occupation at 24th & Pennsylvania Ave. NW. They also need food and supplies on a daily basis. More than anything, they need donations to pay for equipment and other supplies.

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