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## Mothers advocating for young people with medical conditions amid state's COVID-19 vaccine rollout

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Two southeastern Connecticut women who have sons with medical conditions that put them at risk for dire outcomes if they contract COVID-19 say they were stunned last month by Gov. Ned Lamont's adoption of an age-based rollout of the COVID-19 vaccine.

The governor's **Feb. 22 announcement (https://www.theday.com/local-news/20210222/teachers-school-staff-will-be-able-to-get-covid-vaccine-at-special-march-clinics)** that as of March 1 the vaccine would be made available to residents 55 to 64 years of age as well as teachers, school staff and child care providers caught off guard many who had been expecting him to say that those with underlying medical conditions and those working in certain essential jobs would be the next groups eligible for the shots.

Front-line health care workers, first responders, nursing home residents and staff, those 75 and older and then those 65 to 74 had been prioritized in earlier phases of the rollout.

Janice Lamb of Stonington was "highly disappointed" by Lamont's course change, which she said jeopardizes the health of her 22-year-old son, Nathan, who has spina bifida and is severely physically and intellectually disabled. Confined to a wheelchair and prone to infections, he attends a state Department of Developmental Services-approved day program in New London and lives at home.

A study published last week in the New England Journal of Medicine found intellectual disability was second only to advanced age as a risk factor for dying of COVID-19.

Under the state's vaccine-distribution plan, Nathan's family won't be able to schedule a vaccination for him until those from 16 to 34 years of age become eligible May 3

Before then, those 45 to 54 years old will become eligible March 22, and those 35 to 44 will become eligible April 12.

"We live fearfully knowing that he could contract COVID, but felt that the benefits of him being in The Light House program outweighed what he was facing from being home endlessly," Janice Lamb wrote in an email seeking help from Ledge Light Health District. "It also allowed my husband and I to work, as Nathan cannot be left alone to care for himself."

Laura Manfre of Ledyard knows the stresses that come with a child's illness.

Her 20-year-old son, Dante, who underwent a liver transplant that led to a compromised immune system, has to be hospitalized at the first sign of a cold. A sophomore at Hofstra, he's living at home with his parents, a sister and a brother after self-isolating on campus during the fall semester.

"Until he's vaccinated, no one in the family can relax," Manfre said.

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She and her husband, Charles Priebe, can't get the vaccine before March 22, when their age group becomes eligible. Dante and their daughter, Sofia Priebe, a Ledyard High School senior, won't become eligible until May 3. And there's 10-year-old Luca, a Gallup Hill School fifth grader whose parents are reluctant to send him back to school when it reopens in less than two weeks.

"If he brings something home, he's putting his brother at risk," Manfre said. "Do we send him full time for his mental health, where the classroom will be more crowded, or have him go full remote when he's been in a hybrid model? For him to be home full time is not good for him."

Manfre found the governor's rollout-plan reversal "shocking" and believes it's a misstep that can be corrected.

"Connecticut's done as well as anyone could by age, but now we're leaving behind those most at risk for health reasons," she said. "You hear people say, 'We're all in the same boat.' We're not. We're in the same storm, but we're in different boats."

Both Manfre and Lamb believe the governor should amend his age-based vaccine rollout to accommodate those with severe medical conditions. Perhaps a special panel could be created to consider such cases and authorize "specialty medical providers" to vaccinate approved patients in their offices, Manfre said.

"We'd travel an hour or two to New Haven or Hartford if we had to," she said.

Both women have contacted the governor's office and have discussed their situations with state lawmakers.

"It's a very hard situation," said Sen. Heather Somers, R-Groton, who responded to Lamb. "There are no easy answers."

Somers, a member of the legislature's Public Health Committee and the governor's COVID-19 Vaccine Advisory Group, said creating a special panel to consider advancing the priority of those with medical conditions "would just slow down the process," the very thing Lamont hoped to avoid by opting for the age-based approach.

"It would be very, very difficult to implement," she said of a system that prioritizes medical conditions.

Nevertheless, Somers said legislators have asked the governor for a way to open up the process to those with disabilities like Nathan Lamb. Nothing has yet moved forward, she said, other than to offer people the opportunity to be placed on waiting lists of those seeking vaccinations. People on such lists can get shots at vaccination clinics that have leftover doses at the end of a vaccination session due to no-shows.

Sen. Cathy Osten, D-Sprague, who has heard from Manfre, said she also has urged the governor to consider ways to accommodate those who clearly need to be vaccinated to maintain "a normal life." She said she supports the notion of a special panel to consider such cases.

Janice Lamb said the waiting-list option isn't practical in her son's case because of the logistics involved in transporting him and his power wheelchair.

Manfre said on one occasion she had her son Dante wait in the car while she tried to get him a leftover dose and learned that those waiting in line at a clinic were being prioritized by age. Several people in their 60s got the available leftover doses, including one person, Manfre said, who had an appointment in a couple of weeks but wanted a shot sooner so she could travel to Florida.

"That was a hard pill to swallow," Manfre said.

Stephen Mansfield, the Ledge Light Health District health director, said the district maintains a waiting list for its vaccination clinics, as recommended by the governor's office. Anyone can have their name placed on the list, he said, though those willing to wait for a dose are first prioritized among those 55 and older.

"Today, we had a second-dose clinic in Waterford," he said Tuesday. "The night before, we prioritized the top 15 names on the list by age and nothing else, and let them know by email. We tell them where and what time, and if they're interested in coming down, they can."

"We ended up having eight extra doses and had people standing by, all in eligible categories," he said. "Some days, you might not have any in eligible categories," in which case a young person could get a shot.

Manfre and Lamb are not alone in their advocacy for changes in the state's COVID-19 vaccine rollout.

Disability Rights Connecticut has filed a formal complaint with the U.S. Office for Civil Rights at the U.S. Department of Health and Human Services, claiming the state's rollout "constitutes disability discrimination in violation of federal law" and calling on the office to "direct Connecticut to immediately revise its COVID-19 vaccine policy to include individuals with underlying medical conditions, regardless of their age, who are at increased risk of COVID-19 infection ..."

Lamb pointed out that a number of other states are prioritizing those with medical conditions. Georgia, for example, this week began vaccinating adults with intellectual and developmental disabilities and their caregivers, as well as parents of children with complex medical conditions who are at high risk for COVID-19 complications.

In Connecticut, Manfre said, "It's not too late to do the right thing."

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