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‘Our residents are in crisis’: In state-run homes for adults with disabilities, COVID-19 spread quickly

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Peg Pedersen visits her son, Craig, outside the group home for adults with developmental disabilities in Villa Park where he lives on May 16, 2020.(John J. Kim / Chicago Tribune)

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While much of the attention related to COVID-19's impact on vulnerable populations has focused on deaths at nursing homes, infection rates are remarkably high in another kind of residential setting: state-operated centers for adults with cognitive or behavioral disabilities.

As of Thursday, more than 1 in 5 people living in these developmental centers had tested positive for the novel coronavirus, state data shows. That's more than double the infection rate seen in nursing homes and other long-term care facilities, where confirmed cases account for about 7% of residents, according to the Illinois Department of Public Health.

Of about 1,650 people who live in the seven developmental centers, which are scattered throughout the state, at least 355 have tested positive, or 21.5%. Eight residents have died, as have four workers.

These facilities share some characteristics with other congregate-care settings, such as shared living quarters and the need for workers to bathe residents, change diapers and perform other intimate tasks. But the developmental centers face specific challenges in fighting the virus. Many residents can't wash their hands on their own or wear masks. They may not understand why their families aren't coming to visit or why they can't leave the home for their usual activities.

So when COVID-19 arrived in the facilities, it spread quickly.

At Elisabeth Ludeman Developmental Center in Park Forest, 59% of about 340 residents and about 13% of the 900 workers had tested positive for COVID-19 as of Thursday. More than 37% of residents have tested positive at the Jack Mabley Developmental Center in Dixon, in the western part of the state, which has about 112 residents. So have 13% of the roughly 215 workers.



Mental health administrator Lynette Roach offers a face mask to a man entering the Jack Mabley Developmental Center on May 13, 2020. More than 37% of residents have tested positive at Mabley in Dixon.(John J. Kim / Chicago Tribune)

Only the William Fox Developmental Center in Dwight, the smallest of the seven centers with 80 residents, has reported no cases to date.

COVID-19 has been difficult to fight in the state's long-term care facilities, where 7,291 of roughly 100,000 nursing home residents have tested positive for the coronavirus and 2,034 have died from it, according to figures provided by state health officials Thursday.

But "if you were working in a nursing home, probably most of the residents would be able to remember to keep their masks on," said Anne Irving, regional director for AFSCME Council 31, which represents workers in residential facilities that serve people with disabilities.

The precautions taken to protect residents in the centers have also changed their lives dramatically. With all of the facilities closed to visitors since March 12, the adults living there have been cut off from loved ones who normally visit.

"It's hard on residents that have very different cognitive levels," said John Haley, whose 63-year-old sister, Jeanne, lives at Ludeman. Haley is also vice president of Parents and Friends of Ludeman Center.

“Much like a child not understanding fully what’s going on around them, they don’t either,” Haley said. “They don’t know why their family has stopped coming to visit.”

Many residents are used to routine, and those who are able also are used to going to jobs or programs during the day. That has stopped. Instead of group activities, residents may be isolated in their rooms or cottages. Familiar caretakers are wearing protective gear that makes them look different too.



More than 37% of residents have tested positive for the coronavirus at the Jack Mabley Developmental Center in Dixon. (John J. Kim / Chicago Tribune)

“Our residents are not used to seeing us wearing gowns, goggles, face shields, gloves. That personal touch is now through a glove. We aren’t just in crisis — our residents are in crisis,” said Tawny Proulx, who works with residents at Mabley. She is also the local union president.

The Illinois Department of Human Services, which operates the centers, convened an infection control team on March 16 that initiated changes to cleaning and hygiene measures, according to spokeswoman Meghan Powers. Employees are taking residents’ vital signs, including temperatures, twice a day.

At Ludeman, where the outbreak was detected in late March, all residents have now been tested and all staff are being tested as well, with the help of the state, Powers said.

The Illinois National Guard was embedded at Ludeman and at the Shapiro Developmental Center in Kankakee for a week in April to help with health monitoring and temperature checks, Powers said. Additional health care workers are there now, deployed by the State Emergency Operations Center, she added.

At Shapiro, 71 residents had tested positive for the coronavirus as of Thursday — about 15% of the resident population. And at the Murray Developmental Center in Centralia, about 11% of residents had tested positive. Many were asymptomatic; many already have recovered, workers and family members said.

“It’s an incredibly silent and insidious virus,” said Allison Stark, director of Human Services’ Division of Developmental Disabilities. Broader testing at some centers revealed high rates of infection, she said, even if residents had no symptoms.

“That is the reality of this pandemic — despite having the best-laid plans, despite having PPE, despite taking precautions, that it still will spread,” Stark said.

Many Illinois adults with developmental disabilities live not in the state-run centers but in privately operated facilities as well as hundreds of group homes. The state recently began tracking cases in many of the midsize private facilities that often serve people with more significant medical needs and have suffered some severe outbreaks. For example, at Golfview Developmental Center in suburban Cook County, a privately operated 135-bed facility, there have been 94 confirmed coronavirus cases and 10 deaths, according to the state.

Golfview did not respond to a reporter’s request for comment.

But the state says it isn’t tracking cases in smaller group homes, citing privacy issues. Some operators of these facilities, however, have spoken publicly about their efforts to contain the spread of the disease.

Joe Mengoni, vice president of residential and clinical services at United Cerebral Palsy Seguin of Greater Chicago, said his organization has seen two or three UCP group homes where all residents have been infected.

“It’s really tricky to keep them isolated in place when they don’t really understand what’s going on to begin with,” Mengoni said, “and keeping them isolated to their bedrooms is really tricky to manage.”

‘I sure miss you’

Family members of residents of the state-run developmental centers said in interviews that they felt their loved ones are well cared for, given the unsettling circumstances.

But they said they have had to work creatively with center employees to try to stay in touch.

All the centers have “house phones” that parents and guardians can call to speak with employees and check in on loved ones. But to catch a glimpse, families sometimes resort to peering through the windows of homes.

Some are going back to basics, like writing cards.

Rita Winkeler, of Bartelso, used to visit her son Mark, who does not write or speak, at Murray in Centralia at least twice a week.

Now, she said, she’s been using FaceTime to sing to him and see his smile.

And other residents, who are used to seeing her around in person, are reaching out to her.

“I get about three calls, minimum, a day from different (residents),” Winkeler said. “That’s been a real lifeline.”

Winkeler also has some new pen pals.

“Dear Rita,” one handwritten letter began. “I sure miss you so much. I can’t wait (until) this is over.”

The resident had affixed stickers — a panda, a unicorn and a cheeseburger — to the notebook paper. “I miss my workshop. Family. You.”

Early on in the pandemic, the centers had to scramble to obtain adequate protective gear for employees — masks, shoe covers, face shields and gowns. There’s a better supply now than there had been, workers and family members said, but gowns, in particular, have been difficult to keep stocked.

At Ludeman, Haley and the Ludeman parents group made an appeal for as close a substitution for gowns as they could get: rain ponchos. The Chicago White Sox came through with 1,200 and the Chicago Cubs donated 1,000 to use as backup supplies.

Some workers at Murray have been sewing masks for themselves and others.

With the shortages of protective gear easing, employees say they can now focus more on keeping residents busy and cared for.

Dorothy Clare Tessman, a psychiatric mental health nurse practitioner who treats adults with disabilities, said it’s been extremely challenging to explain to the residents why they can’t participate in their daily activities outside their homes or see their friends.

“People are just really struggling to explain that the person hasn’t done anything wrong. A lot of them are like, why can’t I keep going to my day program?” Tessman said. “The families have struggled to explain that this is related to trying to keep you safe.”

Routine weekly outings have stopped, and workers are trying to offer alternatives as they can. Instead of taking residents to a dollar store or Dairy Queen to spend money they earn at their jobs, employees at Mabley are taking orders from residents, shopping on their behalf and delivering everything from a Coke to McDonald’s french fries, Proulx said.

At the same time, many workers’ home lives are upside-down, as they try to avoid bringing the virus home.

Proulx gets home from Mabley in the afternoon, goes straight to her garage, strips out of her clothes and bags them up. Then she goes inside the house, avoids her husband and heads straight

to the basement, where she's made an apartment for herself for the last few weeks. She has an exercise room, a bathroom, a bedroom.



Tawny Proulx dumps her work clothes into the washer after changing at her home on May 13, 2020, in Lyndon, Illinois. (John J. Kim / Chicago Tribune)



Tawny Proulx has been living in her basement to mitigate the risk of exposure for her and her husband, who is also an essential worker.(John J. Kim / Chicago Tribune)

Her husband makes her dinner every day. When it's ready, he rings her phone, leaves the food on paper plates on the stoop and makes himself scarce again.

Proulx puts on her mask, brings her dinner back to the basement and eats it with plastic utensils, alone. She heads back to Mabley at 6:30 a.m. the next day.

So vulnerable, so loved

Those supporting a shift away from larger centers to smaller, community-based homes point to the pandemic as another reason to do so.

At a news conference and rally last week, officials from The Arc of Illinois, which advocates for people with intellectual and developmental disabilities, argued that the developmental centers are inherently more dangerous for residents.

“There are more or less set times — this is the time that I can bathe; this is the time that I can go to the common area. Normally what happens is there's multiple people in a room,” said Nafia Lee, manager for the Going Home Coalition, a group pushing to close developmental centers in favor of community living. “If you have a bathroom with multiple stalls, there's very little privacy.”

The Arc of Illinois called on the state to increase funding for small community settings and move residents out of the centers once the pandemic has eased.

But community-based group homes have been susceptible to COVID-19 outbreaks too as living quarters typically are shared by several clients.

United Cerebral Palsy Seguin of Greater Chicago, based in Cicero, operates 35 shift-staffed homes that house about 170 adults with disabilities. As of Monday, 14 residents had tested positive for COVID-19, according to Sammy Gutierrez, assistant vice president of residential and clinical services.



Peg Pedersen knocks on the door at the group home for adults with developmental disabilities where her son, Craig, lives. Because of the coronavirus, Peg is only allowed to see Craig from a distance outside the Villa Park home. (John J. Kim / Chicago Tribune)



Latex gloves sit atop Peg Pedersen's purse as she dials the number for the caregiver for her son so they can bring him outside for a brief visit.(John J. Kim / Chicago Tribune)

Those who test positive are moved temporarily to a home that wasn't in use; it's become a quarantine house. One worker has died.

Employees at many Seguin homes are working overtime and taking extra shifts, even staying overnight on air mattresses, as some employees have contracted COVID-19 or can't work because of underlying medical conditions, according to Gutierrez.

The residents, meanwhile, are having a hard time adjusting to the new routines, like their counterparts in the larger centers.

"They're depressed. They want to go places. It's sad that our folks are going through this," Gutierrez said. "People are coming to work because they know that our individuals need them now more than ever."

Because state data about COVID-19 outbreaks has been made public only for larger facilities that agreed to release the tallies, it's difficult to know how widespread cases are in other residential settings for people with developmental disabilities.

Sabrina Chapadjiev, whose 53-year-old brother Sammy lives at a facility in Rolling Meadows run by a company called Clearbrook, worries about the outbreak there.

“I found out via my family member that there were two confirmed cases in The Commons, where he lives. I immediately had a panic attack,” she said. President and CEO Tony Di Vittoria said in an email that there have been 16 positive cases and four deaths among residents at The Commons.

Chapadjiev, who grew up in Elk Grove Village and now lives in Brooklyn, has been working to organize donations of protective supplies for Clearbrook employees and created a Facebook group for family members of people with developmental disabilities in Illinois so they can advocate together for emergency help.

The residents are so vulnerable and so deeply loved, she said.

“Just because they’re in there doesn’t mean they’re forgotten by their loved ones. In usual times he’s literally home every weekend, and my mom right now is missing him terribly.”

Staying in contact with loved ones is particularly difficult for people who aren’t able to communicate verbally.



Peg Pedersen reaches out to give a virtual hug to her son, Craig, during a rare outdoor visit to his group home on May 16, 2020. (John J. Kim / Chicago Tribune)

Craig Pedersen is 48 and his mom, Peg, is used to visiting him at least once a week at his small, privately operated group home in Villa Park. She usually brings him food and eats with him,

reads the logbook that details his care for the week, and organizes his clothes in his room. Craig has cognitive, vision and hearing impairments; he uses a wheelchair.

“He cannot speak to me, so it’s been especially difficult. Other people have done Zoom, or I can talk to his caregivers, but it’s not like being with him and seeing him,” Pedersen said. Craig’s birthday was in April; it was his first birthday spent without his mother.

“For all of his life, it’s been difficult that he can’t tell us what he feels. But it’s worse once he isn’t with you.”



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Recently she dropped a meal off for Craig, his housemates and their caregivers. When she left it on the porch, she could see him from a distance through the doorway, but he was too far away to realize she was there. Then, on a particularly warm, sunny day, workers at the home wheeled Craig into the backyard so Pedersen could see him for a moment.

“I just need to see him,” Pedersen recalled she told the workers.

Pedersen came, stood at a distance in her mask — he couldn’t wear one because he wouldn’t understand — and shouted his name.

“Big smile on his face! He could see me and hear my voice,” she said.

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