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SPORTS, 1D

ROCHESTER Democrat and Chronicle

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Jackie Dozier brings groceries and washed laundry to her mother's assisted-living apartment on Clarissa Street in Rochester. Her mother, 85, has dementia and multiple sclerosis. TINA MACINTYRE-YEE/ROCHESTER DEMOCRAT AND CHRONICLE

Outreach helps those who care for loved ones

Local agencies improve connections to resources

Marcia Greenwood
Rochester Democrat and Chronicle
USA TODAY NETWORK

Here and across the country, the coronavirus pandemic has hit African American and Latino communities especially hard.

For people of color already caring for loved ones who are frail and elderly or dealing with other illnesses such as dementia and Alzheimer's disease, the pandemic has added one more chal-

lenge to daily life.

Now, local agencies are working to better connect their caregiver support services to people in underserved communities who might be struggling to cope with the onslaught of demands.

The Rochester & Finger Lakes Region Chapter of the Alzheimer's Association has launched a public information campaign to reach people in need, including in impoverished city of Rochester neighborhoods, said Amanda Drobnica, the association's senior director of programs and services.

The association is also partnering

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"We could not do this without a cadre of staff who come in every day. They have driven hundreds of miles ... all without complaining. They took up the challenge because they see the need."

Mary Rose McBride Vice president of marketing and communications for Lifespan

EDITORIAL

Governor, fix jobless insurance mess now

Broken system just adds to worry, fear and stress

There's raw frustration. There's anger. There's anxiety.

New Yorkers at the epicenter of the world's COVID-19 pandemic have lost family, friends, neighbors, colleagues and acquaintances.

Thousands upon thousands, too, have lost their jobs as the Empire State's economy has ground to a halt. Now, as Gov. Andrew Cuomo and his administration work to start regional reopening strategies, there are some signs of hope. But for too many New Yorkers, there is still considerable concern, fear and stress.

Why? New York's unemployment system is broken.

Governor, please, fix it now. We're not interested in any more excuses at the daily press briefings.

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Longtime grocer dies
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Care

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with Lifespan in offering free help with daily tasks, arranging for deliveries of groceries and prescription medication.

To reach those who need support, the Alzheimer's Association is posting ads in places such as bus shelters and other targeted locations and distributing flyers through other local nonprofits.

Colleen Bober, the association's grants manager, said the group's mailer of virtual programs and services was sent to over 3,600 individuals. In addition, "a weekly email of program information, flyers, etc., is sent to 400 contacts," she said. "Outside of the weekly email, staff electronically distributed 550 flyers."

The effort includes direct contact, as well, said Drobnica. "We are being proactive by calling our caregivers that have reached out for our services previously to check in with them to see how they are being affected by COVID and how their loved ones are doing during this time, especially for this population adversely affected by COVID."

That approach might not reach people who may have been plunged into the role of a family caregiver for the first time during the pandemic and are unaware of resources to get support. But judging from the response, there's a real need among families already connected to these agencies.

The Alzheimer's Association's free services include educational programs, care consultations and support groups. Since the coronavirus crisis emerged, "we have increased our care consultations to the under-served population by 124%," she said. "Of those, 70% were a result of direct staff outreach efforts."

Since March 12, the association has made more than 220 calls to past clients on the underserved call list, said Dina Johnson, the organization's director of care and support. "We conducted roughly 40 care consultations and offered over 40 information and referrals," she said.

Before COVID-19, the association's services were offered in person in places such as the Maplewood YMCA and Charles Settlement House, both in northwest Rochester. Now, amid social distancing, they're available online.

That's both a strength and a limitation, as a large number of people the organization hopes to help do not have internet access. Recognizing this, Drobnica said all of the services are available by phone, as well, by calling the Alzheimer's Association at (800) 272-3900, which is open 24 hours a day.

And what sounds like a simple phone call or computer session isn't always so simple. As Bober explained, "The biggest challenge noted by our constituents is finding a quiet space alone to participate in programs, especially if they are living with their loved one who is living with dementia. But constituents can step away from programs at any time if needed, and our helpline is available 24/7 for constituents when they need."

The association is also connecting family caregivers with emergency deliveries of food, groceries and prescriptions, offered through Lifespan, which can be reached directly at (585) 244-8400 between 8:30 a.m. and 4:30 p.m. Monday through Friday.

In the past five weeks, Lifespan, working with Foodlink and Medical Motors, has gotten 2,300 boxes and bags of free food to people in need who are 60 and older — the majority of whom live in the city of Rochester — said Mary Rose McBride, vice president of marketing and communications for Lifespan.

Lifespan workers also are doing personal shopping on a limited basis for older people who can afford to pay for groceries. Unlike commercial personal-shopping services, Lifespan does not charge for the service.

Such support takes time and staff, so it's not sustainable in the long term. But in the midst of the pandemic crisis, it's a priority. For people living on the brink as they care for a loved one, it's assistance that can prove the difference between making it through another day and slipping into full-blown crisis.

In April, New York state released data showing disparities in the death rates of white, black and Latino patients with COVID-19. African Americans in upstate were worst off, dying at twice the percentage they represent in the population. And a stunning 86% of everyone who has died in New York of COVID-19 had at least one of the pre-existing health-risk factors that make the disease more deadly — many of which are more prevalent among African American and Latino residents.

Working and caring full time

For the past 15 years, Jackie Dozier, 62, of Rochester has looked after her mother, 85, who has dementia and multiple sclerosis. Dozier's mom, who uses a wheelchair, calls an assisted-living apartment home. Her circle of care — which Dozier coordinates and oversees



Jackie Dozier brings groceries to her mother's apartment on Clarissa Street in Rochester.

TINA MACINTYRE-YEE/ROCHESTER DEMOCRAT AND CHRONICLE



Jackie Dozier has overseen her mother's care the past 15 years. Jackie is more hands-on now because of disruptions created by the pandemic. PROVIDED PHOTO

— includes a health aide who visits her in the morning and gives her breakfast. Another aide stops by in the evening and serves her dinner.

Before the pandemic, Dozier's mother attended a day program for seniors. "I didn't have to worry or stress," she said. But by New York state mandate, the program has been shut down. So now, "I am, for the most part, taking care of her during the day," said Dozier. That's on top of working full-time for Trillium Health, supervising its Women's Prevention Program, which she continues to do remotely.

Dozier has installed a webcam in her mom's apartment, "So I can talk to her and see her while I'm not there," she said. "But I'm still running back and forth a lot. It's been challenging." Yet she knows that other caregivers are in worse predicaments.

According to the national Family Caregiver Alliance, African American and Latino caregivers experience higher burdens from caregiving and spend more time, on average, caring for loved ones than their white or Asian American counterparts.

The arrival of the coronavirus has added new layers of hardship.

For instance, because her mom's dementia and MS symptoms have worsened over time, Dozier would like for her to have an overnight aide, too. Finding someone to fill that role would be challenging under normal circumstances; at the moment, it's impossible.

"Definitely, one of the biggest hardships is just not being able to get anyone to help out," said Jenny Thomas, 45, a licensed practical nurse who works at a drug and alcohol treatment facility in Wayne County but previously spent decades supporting family caregivers. In 2019, she took on that role herself when her father was diagnosed with lung cancer.

"In an African American family, most times someone's going to step in," she said. But against the backdrop of the pandemic, people are really being stretched thin.

Numerous studies show that service and essential workers, and people who can't afford to stay home, are disproportionately black and Latino, which makes trying to fill care gaps created by closed programs (as in Dozier's case) incredibly difficult.

In addition, like everyone else living through this pandemic, dependent family members still need to go places such as medical appointments. And they need supplies, from food to toilet paper to medications, Thomas said.

In the city of Rochester — where more than 40 percent of residents are African American, more than 18 percent are Latino and the overall poverty rate exceeds 33 percent — "You have the mom-and-pop corner stores that don't offer the greatest, healthiest food choices," she said.

Suburban stores, which stock better options, are not as accessible, especially for people who rely on public transportation, which opens up yet another discussion. "Imagine sitting on a bus with someone in close proximity for God knows how long," Thomas said.

That has brought a whole new fear, especially for those caring for elderly parents: bringing the virus home.

Dozier has her own car to get around. But being exposed is "consistently on my mind when I walk outside my door," she said.

On a recent Sunday, after taking dinner to her mom, she went to a store. "And I pulled into the parking lot, and there were tons of cars. And I sat there for a minute and put my mask on. But it looked like a normal shopping day."

She decided to forgo shopping that day.

Said Thomas: "I'm sure this pandemic is going to bring a ton of conversation to the table."

'As easy as possible'

"The African-American population is disproportionately affected by Alzheimer's and dementia, and now COVID," Drobnica of the Alzheimer's Association said, "so we're really trying to be front-facing to offer services and resources to this population. It's important that they know we are there for them."

The Alzheimer's Association's initiative predates COVID-19, but its ramped-up outreach effort has come in response to the pandemic.

That effort, including outreach and assistance for things like grocery deliveries, comes with costs, so not every organization is in the position to provide such support. The work is funded through a New York state Department of

About this series:

African American and Hispanic families tend to take care of their own, especially when it comes to caring for a loved one with dementia or other health issues. And the pandemic has hit communities of color especially hard.

The Democrat and Chronicle has been reporting on solutions for caregivers of color in our community, both professional and those who care for loved ones in their homes.

This is the first of three stories in this latest installment of solutions-oriented stories on the top. The second story will look at a grassroots effort to get iPads in the hands of people in under-served communities to promote telemedicine and to reduce isolation. The third story will look at an effort to help professional caregivers stay on the job by addressing whatever challenges that arise amid the pandemic.

This project is funded by a grant from the Solutions Journalism Network.

Health grant and carried out in partnership with Lifespan, which serves the area's aging population as a whole, not just people with Alzheimer's and dementia.

An Alzheimer's Association spokesperson explained there are two grants: one for \$100,000 that specifically targets African Americans and Hispanic residents in eight Rochester ZIP codes: 14605, 14606, 14608, 14609, 14611, 14613, 14619 and 14621. In addition, all seven New York state chapters of the association share a five-year, \$25 million grant targeting a variety of underserved communities throughout the state, including African Americans, Hispanics, LGBTQ, and those living in remote, rural communities.

McBride of Lifespan said their new programs were launched in response to demand caused by the coronavirus crisis — and despite the fact that, of 160 Lifespan employees, only around 25 have been working.

"It's not something we ever thought we'd have to do," but "people just started calling us," she said — including a woman who had gotten down to one sleeve of Ritz crackers as her food supply. "I think a lot of people just buy a little food every week," she said. "Not everyone has a pantry full of food. It's scary."

Initially, Lifespan also was delivering prescription medications to people but has since made arrangements with pharmacies to make the deliveries.

But doing food deliveries alone is no small feat. "We could not do this without a cadre of staff who come in every day," McBride said. "They have driven hundreds of miles, and they do it all without complaining. They took up the challenge because they see the need."

Lifespan does not plan to continue the grocery and medication delivery services once the COVID-19 crisis has passed, McBride said, although its dozens of other programs serving older adults and their caregivers are ongoing.

So, too, are the Alzheimer's Association's offerings.

"Call us," Drobnica said. "We have very highly skilled and trained counselors that can help. ... We're trying to make things as easy as possible."

Every family situation and every caregiver's circumstance is different, she said. But, "We have very highly skilled and trained counselors that can help you through each individual problem."

It's important that people reach out for extra support right now, she said, and "know that they're not alone. There's someone on the other end of the phone."

Reach the reporter at mgreenwo@gannett.com. Follow her on Twitter as [@MarciaGreenwood](https://twitter.com/MarciaGreenwood).