

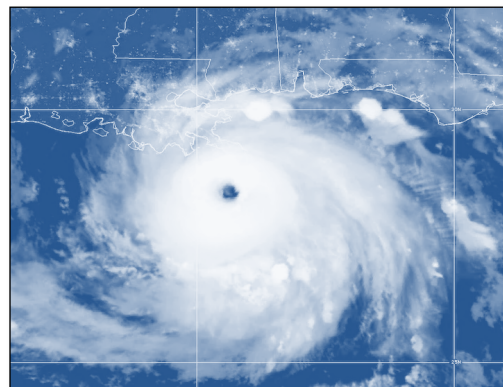
## **Ordinary Heroism: Evacuating Crossroads Louisiana During Hurricane Ida**

By Susan McIlwain and Mary Kay Cowen, with Hugo Dwyer

### ***How do you keep people with Intellectual and Developmental Disabilities safe during a hurricane?***

Since Hurricane Katrina, the state of Louisiana has mandated every facility housing people with I/DD or the elderly to set up an emergency evacuation plan, and to perform annual mock evacuations to ensure that the residents of the facilities will be kept safe. On August 28, 2021, sixteen years to the day after Katrina, Hurricane Ida made landfall in Port Fourchon, just south of New Orleans.

Hurricane Ida was not the first threat to the Louisiana coast this year. Residents track the path and power of each storm to see which one might pose a major threat to their homes and communities. Ida had strengthened and weakened and been somewhat unpredictable in her course for a few days. In late August, it became clear that Ida was growing larger, wetter, and more dangerous, and that she was heading straight towards Southern Louisiana with New Orleans and surrounding areas receiving voluntary and/or mandatory evacuation orders.



Crossroads Louisiana is a non-profit provider founded in 1982 by Dr. Gerald Murphy to serve persons with I/DD in the Greater New Orleans area. Crossroads is currently run by Executive Director Susan McIlwain. The facility now consists of six 6-bed community homes, all ICF certified. They also oversee a Supervised Independent Living (SIL) program in which another 36 individuals live throughout the community in private homes or apartments.

24 hours before Ida was expected to make landfall, Susan made the call to move all of the seventy-two residents to safer ground at Camp Hopewell, a Christian Retreat located some 350 miles to the north in Oxford, MS. This was to be the second time that Crossroads had evacuated to Camp Hopewell, the first being during Hurricane Gustav in 2008. Crossroads has a written procedural manual for evacuation, and the staff had practiced mock evacuations annually, fine tuning and improving the procedures every time. Still, planning and trial runs are one thing. When a crisis hits, it's all about execution.



Staff were contacted and asked if they could join in the evacuation and bring their families, or if they and their families had made other plans. She called on families of the residents, to see if they could help out. Among those families were Mary Kay and Mark Cowen. Mary Kay's brother Tommy is a resident of one of the homes, and her husband Mark had catered many of their meals and was well known to the Crossroads family. Mary Kay and Mark packed up and left early Friday morning, to get to Camp Hopewell to obtain food and set up for the others. Meanwhile, Susan and the staff packed up sheets, towels, adult briefs, games, and anything else that might be needed. They hired a bus, loaded up

Crossroads' 13 mini-buses, and set out with staff and families in their own cars late at night, so that the residents would all have eaten, taken their medications, and be ready to sleep for most of the six- to seven-hour journey to Oxford.

When the caravan arrived the next morning, Mark and Mary Kay had set up to feed the weary travelers. Between the seventy residents, the staff and their families, and the families of the residents who came to help out, the group numbered around 140 people. Due to the Covid pandemic, Camp Hopewell had not been running most of its usual summer programs and retreats, so they were able to accommodate everyone. Families that owned pets had brought their dogs and cats and even a pet lizard (a bearded dragon, to be exact). Beds were assigned to residents and their families, though some of the families chose to relocate to motels nearby.

The evacuation plan had been written with specific tasks and responsibilities assigned to directors, program managers, and supervisors, who then worked with residential staff and volunteers to make sure that all of the residents' needs were being met. It didn't take long for the group to develop a new daily routine, some of it mirroring the daily activities from back home, some of it adjusted to the camp environment, and some of it adapted to the fact that they were working with a smaller staff augmented by volunteers.

Every day meant buying more food and necessities at a nearby Sam's, cooking, cleaning, and of course, keeping the Crossroads residents active and entertained. Remarkably, there were very few incidents during these two weeks, either behavioral or medical, and all were of a minor nature. While the staff and families put in extra effort to make sure everything was running smoothly, the residents generally experienced the evacuation like two weeks at camp. And that's exactly the way it was supposed to be.





"It was non-stop," Susan remarked. "And until we were coming home, I didn't realize how long we had been there. You do this, and do this and do this, and completely lose track of time. You don't even think about it. You just do what you gotta do."

Mary Kay describes watching all of this unfold, and getting to see the daily process of Crossroads' work, "It never ceases to amaze me, what they do. You think you know about what's happening on the surface, going on up front. But until you really experience what's going on in the background, see it from the inside, you really don't understand the challenges it takes to do what Crossroads and people like Crossroads do every day. I thought I had a clue, but this really opened my eyes."

Once the storm had passed, a team of four traveled back to New Orleans to evaluate damage. They spent the day evaluating the situation, confirming that homes were safe, repairs were arranged, refrigerators and freezers were or would be secured or cleaned out. Once staff that remained in New Orleans had confirmed all of the client homes had electricity and usable water to Susan, she signaled that the group return with the least amount of disruption to care. At that point, groceries and other supplies (including gas) were obtained, everyone packed up their things, got back onto the buses and into their cars, and lined up for the caravan back to New Orleans.

The Crossroads group stayed at Camp Hopewell for thirteen days before being able to move back home. They've been back about two days at the time of this writing, and things are nowhere near back to normal. One home remains closed due to a bureaucratic snafu at one of the state agencies. There are still long lines for food and supplies. Folks are settling back in, but it will be a while before everything in New Orleans returns to normal.

The costs of this evacuation were extensive. Food for the group was estimated to have cost anywhere from \$1,000 to over \$1,200 per day. The motel rooms ran about \$5,000 to \$6,000. The bus cost about \$2,500, plus the cost of gas for all of the vehicles. The stay at the campground itself cost about \$30,000. Susan estimates the total for the evacuation will come in at around \$60,000 or higher. Crossroads won't receive any additional state or federal assistance for this evacuation, either. It's all coming out of their own pocket.

Of course, there's that other thing. There's that thing that can't be measured, that thing that can't be written into an evacuation plan or assigned as a task. It's that special thing that you feel, that you can see in the day-to-day workings of a group of ordinary people rising to meet the challenges of extraordinary circumstances. The success of this evacuation, the physical and emotional health of the Crossroads clients, and staff, and all of their families, the ability for everyone to just get it all done for two weeks during a crisis, it all boils down to the love and devotion of those involved. That's what it's all about.

*Mary Kay Cowen has long been a member of the VOR Board of Directors. Susan McIlwain, Executive Director of Crossroads Louisiana, has also served as a member of the Board and has participated in several of our Annual Conferences in Washington, D.C.*



For more information about Crossroads Louisiana, or to make a contribution to help offset the costs of the evacuation, please go to <https://crossroadslouisiana.org/>

### **GOT STORIES?**

VOR always welcomes personal stories and articles from our families on the value of ICF care, the opportunities to develop skills and be part of a community offered by facility-based vocational centers or farmsteads, the importance of a full continuum of care, and the need for a well-paid, well-trained workforce of Direct Support Professionals.

**Please contact us at [info@vor.net](mailto:info@vor.net) for more information.**



## Executive Director's Report

After years of politics as usual and little legislative activity affecting people with intellectual and developmental disabilities, 2021 has been a virtual



roller coaster ride, of twists, turns, and fast descents. The Biden administration and members of the 117<sup>th</sup> Congress have set their sights on providing major funding for people with I/DD and improving wages and training for the workforce of Direct Support Professionals (DSPs) who provide for their support and care. Regrettably, the agenda put forth by the President and Congress has been aimed only at Home and Community-Based Services (HCBS), ignoring the more vulnerable individuals who reside in intermediate care facilities (ICFs) and the DSPs who serve them in their ICF homes. VOR has been working with allies from several like-minded organizations to ensure that increases in funding and improvement of services are meted out fairly, covering *all* people with I/DD and *the entire workforce of health care professionals*.

President Biden's **American Rescue Plan** was proposed shortly after his inauguration in January. It was introduced as the **American Rescue Plan Act (ARPA)** in Congress in February, and was signed into law on March 11, 2021.<sup>1</sup> ARPA provided for a temporary 10 percentage point increase in the amount the federal government would cover for Medicaid services relative to the amount provided by each state (FMAP), but this increase was to benefit HCBS settings only, not ICFs. In other words, if the federal government had covered 50% of the cost of an individual's Medicaid services, and the state covered the other 50%, ARPA would now have the fed cover 60% and the state 40%, but only for HCBS care. ICF funding would remain at whatever rate had previously been established. The goal of the American Rescue Plan was supposed to be to help everyone who had been affected by the COVID-19 pandemic. Nonetheless, neither the 117<sup>th</sup> Congress, nor the Biden administration, nor the well-known "one-size-fits-all" advocacy organizations would acknowledge that people residing in ICFs were also affected by the pandemic, and were also deserving of relief funding.

A few days after ARPA had passed, several Members of Congress put forth proposals for a bill they were considering called the **HCBS Access Act**,<sup>2</sup> seeking input and support for ideas like permanently increasing the federal government's share of funding for people receiving HCBS services to 100%, again while not changing the Federal/State funding ratio for ICF services. If passed, such a proposal would likely have eliminated ICF care in the United States, for governors and state legislators would be incentivized to move everyone in ICFs to HCBS settings in order to shift the entire cost of I/DD care to the federal government. Fortunately, the HCBS Access was never introduced.

Nonetheless, in late June, the same members of congress who had proposed the HCBS Access Act now introduced the **Better Care Better Jobs Act (BCBJ)**.<sup>3</sup> This bill proposed a \$400 Billion increase in federal funding for HCBS services only, along with programs to address the shortage of DSPs by increasing wages and training for caregivers in HCBS settings, though not those who serve in ICFs. *(Note: While some state-operated ICFs have union workers, most private ICFs have non-union workers and rely on the same pool of workers to staff their facilities.)*

It is difficult to believe that authors of BCBJ, the HCBS Access Act, and the American Rescue Plan Act thought that they were helping all people with I/DD and not discriminating against any particular group of individuals, DSPs or providers of residential service when they drafted these bills. According to the bill summary for BCBJ,

*"...the bill provides funds for the Centers for Medicare & Medicaid Services to award planning grants, develop quality measures, and provide technical assistance to states regarding specified HCBS improvements, particularly with respect to access, utilization, and the associated workforce. The bill also increases the Federal Medical Assistance Percentage (i.e., federal matching rate) for HCBS in states that develop plans and meet specified benchmarks for improvements.*

*The bill also makes permanent (1) the Money Follows the Person Rebalancing Demonstration Program (a grant program to help states increase the use of HCBS for long-term care and decrease the use of institutional care."*

On July 4<sup>th</sup>, David Axelrod, a former advisor to President Obama, took a stand against these advocates in an editorial in the New York Times entitled, **"When It Comes To People Like My Daughter, One Size Does Not Fit All"**.<sup>4</sup> Mr. Axelrod and his wife Susan have a daughter with I/DD who resides at Misericordia, multi-setting campus community in Chicago. (Misericordia offers ICF, group home, and own home (assisted) environments, depending on the needs of the individual.) Since writing that letter, Mr. Axelrod reached out to his friends on Capitol Hill and in the Biden administration to advocate for better care for *all* people with I/DD, and better jobs for people working in *all* settings in the Better Care Better Jobs Act. He has also been working with VOR's allies at Together for Choice (TFC), as that group has strong roots in the Misericordia community.

<sup>1</sup> <https://www.congress.gov/bill/117th-congress/house-bill/1319>

<sup>2</sup> <https://debbiedingell.house.gov/news/documentsingle.aspx?DocumentID=2932>

<sup>3</sup> <https://www.congress.gov/bill/117th-congress/house-bill/4131> (House Bill) and <https://www.congress.gov/bill/117th-congress/senate-bill/2210> (Senate Bill)

<sup>4</sup> Links to the Times article and the text of the letter are available on our website at <https://www.vor.net/legislative-voice/advocacy-letters/item/axelrod-letter-to-ny-times-july-4-2021>

TFC's Scott Mendel and I, along with a representative of AFSCME (one of the large unions representing DSPs), have been working with supportive members of the Senate to have ICFs be funded in *parity* to the \$400 Billion in the BCBJ - *i.e.* to be awarded funds in a ratio equivalent to the amount of federal dollars that is currently being allocated to ICF services in relation to the amount allocated to HCBS services. We were told outright by members of HCBS-only advocacy organizations and the offices of certain members of congress that this was *their* \$400 Billion, and we could not be included in it. We would have to ask for money extra funding, on top of the \$400 Billion. But some people still objected. They didn't want to include *our* people in *their* Better Care Better Jobs Act. Period.

So Scott crafted a separate bill, paralleling the language for HCBS funding as written in the BCBJ, and our team worked to adjust the language to make it consistent with protocols and requirements specific to ICFs. Our contacts in Congress supported for this strategy and were ready to introduce this new bill in the Senate, when suddenly, everything took another turn.

In mid-August, BCBJ morphed into the new reconciliation bill, the **Build Back Better Act**.<sup>5</sup> At this writing, the bill has not yet been formally introduced. On the surface, various House committees have been submitting their reports - recommendations for their priorities within the framework of suggested funding allocations. - while behind the scenes, key members of the House and Senate are horse-trading - making their own demands, awarding concessions, and crafting the language of key provisions. Our best hopes for parity funding may well lie in the manner in which the Senate will influence the way House bill is written, before it is even introduced. We continue to reach out to decision makers to include our loved ones in whatever funding they provide.

At this juncture, it appears that Congress will approve far less than the \$400 Billion for HCBS services that disability advocates have requested. This is, of course, disappointing to us, as we advocate for high quality care for *all* people with I/DD, regardless of the setting, and we acknowledge the need for vast improvement in the HCBS system. Nonetheless, we advocate for a system that recognizes the diversity of the community of people with I/DD, and that will ensure the right to choose from a full range of services and residential options. We ask that Congress allocate funds with equanimity, not favoring any one group of individuals or services over any other.

Also included in the Build Back Better Bill is a provision to grant the permanent re-authorization of the **Money Follows the Person Rebalancing Act** (MFP). VOR continues to object to this idea. While MFP is well hyped by certain advocacy groups, and incredibly popular in the media, this program has had unintended consequences. MFP has not only been used to "rebalance" the ratio of people receiving ICF and HCBS services, but that is has been used to eliminate ICFs entirely in several states, and continues to do so, exceeding any pretense of "balance". We find it discouraging that Congress has never admitted this problem, nor seen fit to evaluate the "unintended" consequences, and never listened to the voices of people who have been discriminated against by this bill. Money Follows the Person has never has never set a goal for what the correct "balance" between services might be, never included any way to critically measure its success or failure. If permanently reauthorized, the program will proceed with no end in sight and will likely continue "rebalancing" until there are no intermediate care facilities left in this nation, and our most vulnerable citizens are subject to the flaws and failures that plague the HCBS system.

While the Raise the Wage Act has not been included in the reconciliation bill, Representative Bobby Scott, Chairman of the House Committee on Education and Labor, has submitted language in his committee report that mirrors some of the provisions in his **Transformation to Competitive Integrated Employment Act**.<sup>6</sup> These measures would provide funding for existing vocational centers for people with I/DD to transition their employment opportunities from sheltered workshops to competitive employment facilities. While the language does not specifically call for the elimination of sheltered employment opportunities or 14(c) wage certificates, it does send a foreboding message to providers that the writing is on the wall, and that zealous advocates will continue to press their determination eliminate these unique employment opportunities for people with I/DD and autism, despite the fact that 100,000 to 125,000 individuals are happily engaged in this form of supported employment.

One bit of good news is that the House Committee on Education and Labor has recommended increasing wages and training for Direct Support Professionals without specifying that their recommendation applies only to those working in HCBS settings. We hope that this equanimity carries into the final bill. All caregivers deserve recognition, career-path education and training, and wages that are commensurate with those of other health care professionals.

We would like to thank Gayle Gerdes at Health Policy Source who has helped us strategize on these issues and arranged meetings with key congressional offices. Thanks to our Presidents Sam Friedman and Harris Capps, our Legislative Committee, our Issues/Oversight Committee for the work they have contributed, and to the many family groups and organizations that have worked with us and supported our initiatives throughout this tumultuous process.

At this writing, there is no clear time line for when Congress will introduce and begin negotiating the BBB Act. As hard as they worked on it in the last month, they are now engaged in negotiating funds to continue operating the government, at least through December, and increasing the debt ceiling. Depending on what happens behind closed doors, this reconciliation bill may be passed by the time you read this, or it may not see the light of day until November or December. Stay tuned.

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<sup>5</sup> <https://budget.house.gov/publications/report/2022-budget-resolution-and-reconciliation>

<sup>6</sup> <https://www.congress.gov/bill/117th-congress/house-bill/2373>



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Fall, 2021NL

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