

# FLORIDA DISABILITY REPORT 2021

Updates on Health Care Access and Social Barriers for Florida's Disability Community







People with disabling conditions consistently have poorer health status, more limited health care access, and lower overall quality of life than their non-disabled peers in society. These disparities of health conditions exist for individuals with intellectual and developmental disabilities (IDD) and individuals with other types of acquired or innate disabling conditions <sup>1-4</sup>. Improving the health, health care, and overall quality of life for this community will enhance their contributions and reduce the societal inequities they currently experience. These improvements would have far-reaching effects as the CDC reports nationally 1 in 4 U.S. adults have some type of functional disability. In Florida, the rate is even higher at 28%<sup>5</sup>. Furthermore, as people age, their risk of developing a disability increases<sup>4,5</sup>.

It's important to shift our understanding of health as "the ability to adapt and to self-manage, in the face of social, physical and emotional challenge". It is a more comprehensive frame for how the public and policymakers should address health and social policy decision-making. However, promoting the best possible health outcomes for the population with disabling conditions requires seeing the world from the viewpoint of the people with different needs and applying the social model of disability. This social model does not view the functional impairment as the disability. Rather the disability comes from the social or environmental barriers that constrain mobility, communication, or other necessary functions<sup>4,7</sup>.

# METHODOLOGY: CENTERING THE REAL EXPERIENCES OF FLORIDIANS

Taking the social model approach, Florida Voices for Health invited individuals with a wide variety of disabling conditions, their families, and advocates from all parts of Florida to participate in seven virtual roundtable discussions (summer 2021). Together, we discussed the social and environmental barriers that affect their health and access to a variety of health care services. This report summarizes the perspectives of the participants from these sessions. Participants in the roundtable sessions included representation from individuals across the lifespan. Parents and caregivers of individuals of all ages with developmental conditions that impair movement, communication, social interaction, and cognition participated. Adults of all ages with acquired disabling conditions that affect mobility, sight, hearing, and other invisible disabling conditions offered their unique experiences of interactions with Florida's health care systems. Collectively, they ultimately pointed to several systemic and social barriers to achieving their full potential of life and health.



## GAPS IN HEALTH INSURANCE COVERAGE FOR FLORIDIANS WITH DISABILITIES

Most participants reported using at least one public payer (Medicare, Medicaid, or Veteran's Administration). Others used more than one public payer or combined a public program with an employer-based insurance program.

#### **MEDICAID**

Home and community-based services are essential to optimize health. The individuals who receive these services report using public and private health plans to pay for their essential needs. The state's Medicaid waiver program, Florida IBudget waiver pays for HCBS for individuals with developmental and intellectual disabilities (IDD). However, there is a waitlist of 22,734 eligible individuals to receive these services as of August 2021, nearly the same number as the people currently being served<sup>10</sup>. Florida consolidated nearly all the condition-specific Medicaid HCBS waiver programs into the Statewide Medicaid Managed Care Long Term Services and Supports waiver (SMMC-LTS) in 2014. There are currently about 50,000 adults in Florida on the waitlist for receiving benefits through this waiver<sup>11</sup>.

Individuals who rely solely on the Statewide Medicaid Managed Care Long-Term Care (SMMC LTC) Waiver also reported difficulties obtaining services. The issues have worsened as the programs have changed over time.



Where I used to be under the Brain and Spinal Cord Waiver program, but they phased that waiver out.... What I used to be able to do if things weren't right was call the administration of the Brain and Spinal Cord Injury Program's (BSCIP) waiver program, and they would be able to sort things out. I would get some sort of resolution. Cause what happens now is they just push it down the road they say the agencies or AHCA would take whatever they say, and that's not it.

Unfortunately, participants of our roundtable sessions reported that delivery of home services is sometimes unreliable or even not available through some of the Florida SMMC LTC plans.



I'm in the health management program, and I need physical therapy. They don't have the necessary folks in the area. If somebody from the agency doesn't show up, then you don't have that particular service that you need. When it comes to eating a meal, if that person doesn't show up, then you don't eat, and if you don't have somebody to call. Oh, you in real big trouble.

### MEDICARE IMPROVES HEALTH CARE ACCESS

Most people who acquire a disabling condition before reaching the standard Medicare eligibility age of 65 must wait for Medicare disability coverage for the two-year waiting period. This period is often during the time they most need diagnostic and therapeutic care and support. The participants who transitioned to Medicare or became dually eligible for Medicare and Medicaid reported access to care and payment became easier and more efficient.



I believe the only reason why I've had positive experiences now with healthcare is because I receive Medicare and dual Medicare, Medicaid, up through Humana. And so, everything I have is covered. I don't have to pay anything out of pocket. You know, as a disabled woman and person, you know we have our cost of living is \$17,000 higher than an able-bodied or nor-typical person.



# ADDITIONAL BARRIERS TO RECEIVING **HEALTH CARE**

The participants of the roundtable sessions identified several barriers to their receipt of quality health care services. Some of the issues related to out-of-pocket costs, but other reasons were more about the structural conditions of the health care systems.

#### LACK OF SERVICE PROVIDERS

The roundtable participants reported that accessing in-network providers had varying levels of difficulty. However, in general, locating network providers of any type who can provide excellent care adapted to the clients' disabling conditions is a persistent barrier.

#### Medical providers

Participants reported that using their established providers often is near impossible as the networks of employer-based and Medicare Advantage plans change. Finding providers within the Florida SMMC programs is even more difficult. One mother lamented the lack of complex specialty care available for her son on her employerbased plan.



We have some challenges and trying to get appointments for my son. And I would just say, just in general for Orlando, we, we lack specialists. It doesn't matter if it's psychiatry, neurology, endocrinology. Anything beyond your average high blood pressure or, you know, cholesterol issues. It's really difficult to find somebody. People don't know what to do with it. You know, I mean, primary care just sort of throws their hands up. I mean, I'm giving him health store supplements for lack of anything better.



Locating providers who had skill and willingness to accept an adult client with a cognitive or developmental disability was an insurmountable task for another mother:



We've had a lot of trouble with, I guess, transitioning from pediatrics to adult care. It's been great difficulty in finding a psychiatrist to the point of I've just given up. Also, just, you know, not a lot of options for, I guess, developmental specialists for that age group.

One participant was from a state advocacy agency that quantifies the lack of community-based long-term service providers in Florida. She offered some potential causes for this deficit.



And we're in the process right now of trying to document the fact that we're having trouble accessing services because a lack of direct support personnel because of low wages and, and probably fear of COVID. And people are having trouble getting, finding providers right now for everything. And people are starting to get placed in intermediate care facilities. And they're literally unable to find care. It's a real crisis right now.

## **Durable Medical Equipment**

Durable medical equipment (DME) provides essential support to many people with varieties of disabilities. They allow them to overcome the many structural barriers to interacting in employment, educational, and social settings. Despite DME's obvious value to individuals with disabling conditions, the participants consistently reported that their greatest difficulties are obtaining and maintaining their equipment. One participant explicitly described how using a wheelchair significantly extended her ability to be employed.



For things like a wheelchair...they say you don't get a new one for five years, but nobody comes to do maintenance on it. Like it gets a flat tire, then it takes months to repair, and you are without a chair all that time before they come out to fix. I've had to drop classes because I would have failed out had I not dropped the class because the W.C. was broke.

And one time the wheelchair was out of service;-I couldn't move the chairthey told me in order to get the chair repaired that I had to go to the doctor's office so he could write a prescription [to repair the chair]. So, I'm saying, if the chair is broken, how could I get to the doctor's office to get a prescription to repair the chair?

Another example of DME that enhances health outcomes for individuals is hearing aids for deaf and hard-of-hearing individuals.



I'm paying a lot of my own hearing expenses out of my pocket because insurance carriers ... tend not to pay for hearing aids. I have to replace them every, I don't know, five to seven years, and that's several thousand dollars per aide, and I wear two. So, we're talking a lot of money. Yeah, they break. They need to be cleaned. All that kind of stuff costs money. So, it's an expensive disability to have.

### Oral health providers

Oral health care is especially difficult to obtain for most of the roundtable participants. Medicaid enrollees older than 21 years generally do not qualify for plans that provide anything other than emergency dental care. Participants enrolled in Medicaid plans reported difficulties in accessing even the limited set of benefits. For some, the dental offices did not have the capacity to care for individuals with a disability.



But my main issue is, there is no dentist that will take him. And I could give them the whole scenario; they'll say, "Okay." And they'll have you come into the office. And then they'll say, "Oh, we can't see him. We're not equipped to see him," even though I had explained his condition to them at the beginning [when she made the appointment].



Even when individuals successfully identify active dentists on the provider network lists, other barriers remain. For example, a participant described getting an appointment as unrealistic due to distance and limited appointment availability.



Another issue is lack of available appointments. I mean, some of the Medicaid providers only provide services on a specific day of the week. You know a few of the other individuals here mentioned, lack of dental offices, that is another big issue. Some of the parents have to drive 30 minutes to an hour to a dentist to take their child, and the parents can't take off work.

A representative from the University of Florida Dental School who works in a clinic that serves clients with special needs validated these experiences. He noted that:



We've noticed repeatedly on a daily basis that for people with disabling conditions, the lack of dental care is extremely bad.



**OUT OF POCKET COSTS** 

Health care services are expensive for most people. However, for individuals with additional expenses related to their disabling conditions, these costs can become insurmountable. More than one of the participants in the roundtable discussions made comments similar to this statement:



Disability has never been something for people that are poor because things are expensive.

#### Oral health expenses

The mother of a daughter with developmental disabilities explained that due to denial of benefits from her dual-eligible plan, she had to pay for most of her daughter's dental care:



She had some wisdom teeth that needed to be removed, and the oral dentist would remove one, but not the other two. So, we had to go to a specialist, and I paid \$1,500, Out of pocket...he removed them out of my pocket. We have Humana HMO. She does Medicare and Medicaid because she's on APD.

Adult participants of our groups explained that Medicare and Medicaid do not cover most adult dental services. Instead, they must pay directly for the dental care they receive. As a result, they frequently forego needed services:



Oral health is horrible. I went to a dentist four years ago, and I haven't been able to get an appointment since.

Being on social security, I don't have the money to even go for the plan. I guess it's a plan through Medicare where you get the dental and the eye, but I don't have any money to contribute to that for my own eye and dental care.

And I went to see a dentist,...and they told me I needed dentures and gave me a referral to someplace in Tampa. [1] called there, and there's no free help at all. And dentures or any kind of implants are going to cost—thousands upon thousands of dollars. So, I don't know what I'm going to do.

[10 made an appointment after going through the process of getting a special authorization because I have Medicare and Medicaid. I could do it – takes at least three months. After that, I could make an appointment - that's another 2,3 months. Now you're talking about six months with a toothache. When I did go, I wasn't able to see the dentist because ...the special authorization ran out. I wasn't able to see that dentist. It was horrible.

Another adult described his experience using a dental school clinic for his care because it provided a significant discount for the service over a private provider. His Medicare/Medicaid dual plan did not include any benefits for dental care services.



[E] ventually, I had to go through student dentistry where students were able to do extractions and make me dentures. Which was really painful because they were learning; it was a learning experience. I mean, my dentures still aren't right. But just going through Medicaid, I was limited on what I could get. They didn't cover any extraction or anything like that. It came out of my pocket, but at least going through a dental school with students learning to become dentists, I got it at a little lower cost.



# **DIFFICULTY NAVIGATING HEALTH PLAN PROCESSES AND RULES**

For individuals with disabling conditions, the widely recognized complexity of the US health care system not only slows their access, at it can completely block their ability to obtain essential services<sup>1,13</sup>. The participants confirmed that rule changes, frequent reauthorization requirements, benefit denials and appeals, and being "waitlisted" for services were some of the processes that most inhibited their access to care.

#### PROGRAM AND RULE CHANGES

Policymakers and regulators change how all public programs are administered based on legislative directives and budgetary limitations. Unfortunately, the roundtable participants reported the changes sometimes have unintended consequences that impede the enrollees' continuity of care providers and access to services.



I had some services that what Medicaid didn't pick up, the waiver picks up. These were things that were available with straight Medicaid that aren't available to me anymore.

They would take away something else. So now they've terminated his speech therapy, they've terminated his occupational therapy. They've taken away his ADT day rate.



A participant described obstacles she met when trying to locate a participating provider after a rule change. She went directly to the state agency (APD) responsible for overseeing the service delivery:



[N]obody answers the phone, or you leave a message... For an emergency at three weeks later, you get a call back after five phone calls. Or when you send paperwork up to get processed, and six months later, after 15 phone calls, it's still there. Somebody has to be held accountable.

#### FREQUENT REAUTHORIZATIONS REQUIRED

Each of the services an enrollee receives through most public and private health care plans must be authorized for payment. Some plans frequently change the authorization period, or the authorization time frames may differ for different services. All of this increases the number of interruptions to needed services. As several participants reported:



We were having to reauthorize the behavioral services... for the last two times, every time we went in.

Reauthorizations are also frequently required when individuals transition care between different specialty providers, resulting in care delays and sometimes denials of needed services:



The interim created long delays when I had to gather all of the medical records and authorizations from three separate physicians of my care. I'm under their care. They were in the process of that when my care was interrupted by COVID.

#### **DENIAL AND APPEAL OF BENEFITS**

Necessary services are sometimes denied, and the enrollees and their family care providers must go through lengthy appeal processes to receive the benefits that the plan authorizes. Families often have to resort to paying advocates or attorneys to receive their entitled benefits.





I have a basket with probably a thousand pieces of paper on trying to access services for him. And when you ask, they say, "Go to due process." They deny it. And, you know, we just don't have good legal representation.

> And like when she had her oral surgery and had her two impacted wisdom teeth. He [the oral surgeon] said absolutely don't have the client call me, have somebody from APD call so that I can talk to APD [to get authorization]. Unfortunately, it didn't help me.

And I'm sorry, I don't think the agency should have the ability to deny services that therapists have requested and state they need doctors have given you prescriptions. And yet the agency determines no, they don't want to give you services.

#### WAIVER WAIT LISTS

budgetary decisions that Florida as applied to the state spending for services for people



It's truly a crisis in Florida, and I know that other states are having issues, but when you're ranked 50th in funding for the Home and Communitybased Service Waiver and 46th in funding for the Long-Term Supports and Services Waiver.

In fact, reports from the Florida Developmental Disabilities Council and the University of



[H]e's been on it since one week after his third birthday. So we're now at 14 years and counting. We've stayed at the lowest level...We need to be in crisis. And when they say crisis, they mean. CRISIS! That you literally cannot take care of him, or if he's a danger to others, or if I have a terminal illness. [A]nd there's 23,000 families on this waitlist.

#### UNRELIABLE OR POOR-QUALITY CARE

Some roundtable participants reported that the vital services often lacked quality or were unreliable in their availability. These conditions ultimately create a significant gap between the services needed and the services provided. Participants reported having difficulty accessing therapies and necessary food delivery, transportation to medical appointments, and oral health services, comprising their home-based care.

One participant described the poor quality of home-based therapies as having inconsistent care providers who lacked the training to manage his special needs:



When folks come out, they're not trained. They don't know how to take care of a quad. And then you have the fact that when folks come out from different agencies don't, most of them say they don't do your service area at all. Instead of for me, when somebody just grabbed your arm and, you know, both my shoulders have been broken, I crushed three bones in my neck. You can't grab me any kind of way because you will break it.

Some participants described transportation services needed to get to medical appointments as undependable. They relayed anecdotes of missed appointments because transportation services were late or simply didn't show up at all as scheduled. This unreliable service delivery even extended to reports of meal services not delivering as schedule and one participant expressed the situation this way:

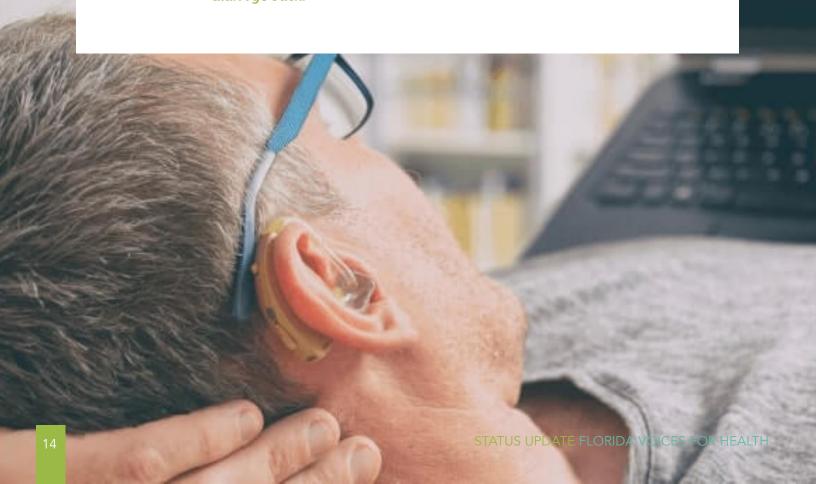


I got a new chair, and the new chair isn't working right. It caused my legs to get numb from something that went wrong with the measurements, so right now, I don't have a chair. So, I need a stretcher service. Well, I had a doctor appointment today so they can do the measurements for the chair. They never showed up. The transportation people never showed up. Okay. That was just today.

Dental health care was consistently noted as a service where poor-quality care appeared evident to participants of all ages. One adult participant explained the dental provider could not adapt to her needs that her disabling condition presented and treated her in a harsh and uncompassionate manner:



I had to find a new dentist because the dentist we were going to use when he had to extract a tooth told me to be quiet. When I was grunting in pain as he was extracting my tooth because I cannot take the Novocain... because my heart can't tolerate it. So he told me to keep it down because there were people in the other rooms who were getting procedures done, and I was going to scare them. So, I left after he extracted my tooth, and I didn't go back.



#### ADAPTATIONS TO DISABILITIES BY HEALTH CARE PROVIDERS

The conversations made it evident that many health care providers struggle to adapt their care to meet the varied needs of people with disabling conditions.

#### **Expected limited-service delivery**

Some participants acknowledged that they had come to expect the lack of adaptations through the years and accepted that providers would be limited in some aspects of their service delivery. One participant summed up his lack of expectations regarding communication of health information in this way:



Of course, the problem came with doctors not knowing what to do and how to give me the information. I just learned to kind of adapt and not expect a lot because I wasn't going to get a lot.

This reality likely contributes significantly to the documented health care disparities that people with disabling conditions experience4. Participants described how equipment for screening and diagnosis did not accommodate their needs and eliminated opportunities for health screenings. One participant described a few such barriers she had encountered:



When I went for my mammogram last year and this year, they did not check the lymph nodes in my other breast because I've gotten to have such limited motion that they couldn't get the machine up there. I was getting an eye exam because I was on a medication that might affect my peripheral vision... They finally gave up doing that because I can't rest my chin and keep my cocked my head up. What the response is: Oh, well, you really don't need it anyway.... I've been to places to get an x-ray, and the table does not move. So I say, well, I need someone to lift me onto the table.... And they reply, "Oh, we can't do that," so the x-ray doesn't happen.

Even for life-saving therapeutic care, individuals encounter barriers when the physical equipment impedes their ability to receive treatments.



I had breast cancer, but when I went to see about the option of doing radiation, I realized that I couldn't get into the machine. I would have had to crawl into it, which I can't do.... So, they said, well, you can't do radiation.

Communication barriers are also an impediment to receiving high-quality and timely care for many people with disabling conditions. Requiring the written or electronic completion of personal information forms can create barriers for individuals with limited sight or writing capacities. Receiving printed material as health education is



spoke about specific instances where the lack of these types of accommodation negatively impacted their care:



Some doctors require you to fill out forms online, but their online forms are not accessible. Sometimes the staff don't want to do that for you, or they want you to take it home and have somebody do it for you. Some of them are more cooperative and do it for you. However, frequently...you're sitting in the waiting room, and the person comes out and reads the form for you to dictate what you're supposed to write on the form in front of all the people that are sitting there, which is not really accessible or secret.

Caregivers and parents of individuals with disabling conditions explained there is a lack of dentists who are able and willing to care for individuals with disabling conditions. For some clients, accommodations for dental care may include specific equipment, specific training, or specific capacity to provide advanced or specialized services. The client participants validated the oral health professional's observation that there is a shortage of oral health providers who have the capacity to deliver services to clients with disabling conditions.



The dental providers, Medicaid dental providers, don't understand how to treat children with special needs. They don't have the experience. They're not trained. They feel uncomfortable treating special needs children.

They're very quick to put them under or suggest sedation. Or to pull out their teeth instead of actually providing the treatment that they need.

# SOCIAL AND ENVIRONMENTAL FACTORS FOR INDIVIDUALS WITH DISABLING CONDITIONS

The overall effect of disabling conditions on an individual's life is not just a result of receiving health care. Overall health is also impacted by how society signals inherent respect and dignity to individuals with disabling conditions and their families. Society conveys these values through interpersonal interactions and private and public local, state, and national policies. Unfortunately, society often overlooks opportunities for inclusion and accommodation while actively perpetuating the stigma associated with disabilities. The key areas that indicate respect and value include accommodations for transportation needs that account for various disabling conditions.

#### **TRANSPORTATION**

The roundtable participants described transportation limitations as factors that consume much of their attention and time, impacting their health care.

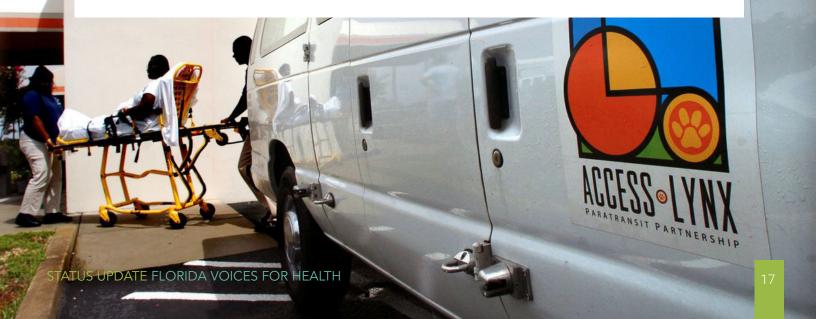


Being able to get to a doctor's office is really difficult at times. Number one, if you take the regular bus...if you get off the bus, where do you go? How do you get to the door? How do you find a bus stop? Or some of us use paratransit, which does help to some extent. But making an appointment and getting to the appointment, it depends on whether there's transportation there, whether the person can find where they need to go.

[I] qualify for paratransit. But they have very limited hours. [A]nd towns or counties don't necessarily have reciprocal paratransit agreements.

[In Miami] ... when it comes to stretcher service, paratransit doesn't do that.

I had a doctor's appointment. And it took me, I think, you know, four and a half to get there taking the fixed bus route.



One participant explained how the built environment inherently excludes participation from people who rely on public transit.



They built a medical facility called Twin Lakes. It was not on the bus line, and the doctor moved over there. So she wasn't able [to see the doctor] unless she paid for a cab, which she did not have the income. Do you do that on a regular basis? She was stuck.



#### **STIGMA**

The participants acknowledged that society is still far from full inclusion and respect for all individuals with disabilities. They pointed out how funding levels for health care and general supports signal that people with disabilities are valued less. They also reflected on how the attitudes of lay people and health professionals continue to convey stigma and lack of regard.



His needs are considerably higher than your average person. What I don't get is why Medicaid pays less. What, apart from making it even harder than it already is achieved by that? Because this second-class citizen is, is really what he's made into. Apart from signaling that you're not as important as people... able to earn their health insurance, I don't see what it does.

Yeah, and once people find out what your disability is, they're going to go after that, and they're going to use it on you. So, you have to make a mental judgment when you're safe enough to show your vulnerability.

## CONCLUSION

The lived experiences of the roundtable participants reveal significant disparities in health access and outcomes for Floridians with disabilities. Families are left to navigate the barriers of affordability, provider availability and competence, limited and unreliable support services, and access to basic coverage.

It's clear that to achieve health equity for Floridians with disabilities, policymakers must be informed by the real experiences of those who rely on the health care system. Those stories should be considered at every step of the process including design, implementation, and beyond. Fortunately, there are multiple evidence-based solutions available to lawmakers committed to these issues. The first step in creating a more equitable system is to simply reframe how decisionmakers and society thinks about disabilities to reflect their true value.

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