



ORAL HEALTH ACCESS FOR FLORIDIANS WITH DISABILITIES:

2021-22 Status Report



FRAMEWORK TO INTERPRETING FLORIDA'S LANDSCAPE

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 conditions¹⁻⁴. 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%⁵. Furthermore, as people age, their risk of developing a disability increases^{4,5}.

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"⁶. 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^{7,8}. 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^{4,7}.



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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.



SIGNIFICANT BARRIERS TO RECEIVING ORAL 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 ORAL HEALTH PROVIDERS

The roundtable participants reported that locating network providers of any type who can provide excellent care adapted to the clients' disabling conditions is a persistent barrier. 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. [I] 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.

[I] 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.

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.

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.

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.



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.

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. 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.





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.

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.

REFERENCES

1. Ervin DA, Hennen B, Merrick J, Morad M. Healthcare for persons with intellectual and developmental disability in the community. *Front Public Health* 2014;2:83. <https://doi.org/10.3389/fpubh.2014.00083>
2. Ulrich MR. Health Affairs blog post: challenges for people with disabilities within the health care safety net. *Yale J Health Policy Law Ethics* 2015;15(1):247-50.
3. Yee S Health and health care disparities among people with disabilities. 2011. "<https://dredf.org/public-policy/health-access-to-care-old/health-and-health-care-disparities-among-people-with-disabilities/>".
4. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health* 2015;105 Suppl 2(Suppl 2):S198-206. <https://doi.org/10.2105/ajph.2014.302182>
5. Centers for Disease Control and Prevention (CDC) Disability & Health U.S. State Profile Data: Adults 18+ years of age. Atlanta, GA: 2021. "<https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/index.html>".
6. Jambroes M, Nederland T, Kaljouw M, et al. Implications of health as 'the ability to adapt and self-manage' for public health policy: a qualitative study. *Eur J Public Health* 2016;26(3):412-6. <https://doi.org/10.1093/eurpub/ckv206>
7. Goering S. Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine* 2015;8(2):134-38. <https://doi.org/10.1007/s12178-015-9273-z>
8. Oliver M. The social model of disability: thirty years on. *Disability & Society* 2013;28(7):1024-26. <https://doi.org/10.1080/09687599.2013.818773>
9. Perkins EA, Kose L, Hooper M. End the Wait! Developmental Disability Policy Brief. Florida Center for Inclusive Communities/Florida Developmental Disabilities Council: Florida Center for Inclusive Communities/Florida Developmental Disabilities Council; 2021.
10. USF FCfCa Floridians on the D.D. waitlist. Tampa, FL: University of South Florida 2021. "<http://ddwaitlist.cbcs.usf.edu/index.cfm>". 2021.
11. Elderly service & waivers. [Elderlywaiver.com](http://elderlywaiver.com/state/florida.html) 2021. "<http://elderlywaiver.com/state/florida.html>".
12. Florida Center for Inclusive Communities at USF About the iBudget D.D. Waiver and Waitlist. Tampa, FL: 2021. "<http://ddwaitlist.cbcs.usf.edu/about.html>".
13. Rich E, Lipson D, Libersky J, Parchman M. (2012). Coordinating Care for Adults With Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions (AHRQ Publication No. 12-0010-EF).
14. Tanis ES, Lulinski A, Wu J, Braddock D, Hemp R. (2020). The State of the States in intellectual and Developmental Disabilities. www.stateofthestates.org
15. Borowsky H, Morinis L, Garg M. Disability and Ableism in Medicine: A Curriculum for Medical Students. *MedEdPORTAL* 2021;17:11073. https://doi.org/doi:10.15766/mep_2374-8265.11073