



FLORIDA 2021 DISABILITY REPORT SUMMARY

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



FRAMEWORK TO INTERPRETING FLORIDA'S LANDSCAPE

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). This report summarizes the perspectives of the participants from these sessions. Participants in the roundtable sessions included representation from individuals across the lifespan. 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

MEDICAID

- The state's Medicaid waiver program, Florida IBudget waiver pays for Home and community-based services (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) 10.
- Individuals who rely solely on the Statewide Medicaid Managed Care Long-Term Care (SMMC LTC) Waiver reported difficulties obtaining services. The issues have worsened as the programs have changed over time.
- Delivery of home services is sometimes unreliable or even not available through some of the Florida SMMC LTC plans.

MEDICARE IMPROVES HEALTH CARE ACCESS

- 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.

ADDITIONAL BARRIERS TO RECEIVING HEALTH CARE

LACK OF SERVICE PROVIDERS

- 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.
- 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.

Durable Medical Equipment

- Participants consistently reported that their greatest difficulties are obtaining and maintaining their equipment (ex: wheelchairs, hearing aids)

Oral health providers

- 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.
- A participant described getting an appointment as unrealistic due to distance and limited appointment availability.

OUT OF POCKET COSTS

- 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."*
- 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.

DIFFICULTY NAVIGATING HEALTH PLAN PROCESSES AND RULES

Program and rule changes

- The roundtable participants reported the changes sometimes have unintended consequences that impede the enrollees' continuity of care providers and access to services.

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

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.

Waiver Wait Lists

- Participants reported they had been waiting for nearly all of their children's lives to be granted access to the Florida Medicaid waiver for people with developmental disabilities.
- In fact, reports from the Florida Developmental Disabilities Council and the University of Colorado Administration on Disabilities found that the Florida iBudget Waiver's funding has decreased annually since 2007. Florida is currently ranked 49th out of 50 states for per capita spending on services for people with disabilities.



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.
- Some participants described transportation services needed to get to medical appointments as undependable.
- Dental health care was consistently noted as a service where poor-quality care appeared evident to participants of all ages.

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.
- Participants described how equipment for screening and diagnosis did not accommodate their needs and eliminated opportunities for health screenings.
- Even for life-saving therapeutic care, individuals encounter barriers when the physical equipment impedes their ability to receive treatments.

Communication barriers

- 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 problematic for people with low vision.



SOCIAL AND ENVIRONMENTAL FACTORS FOR INDIVIDUALS WITH DISABLING CONDITIONS

TRANSPORTATION

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

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.