The Multi-Layered Maze of Navigating the Healthcare System for People with Mobility Disabilities in New York

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Executive Summary

This Needs Assessment Report examined the experiences of people with mobility disabilities and their healthcare providers when accessing care in New York State. Through four focus groups, we identified a complex, multi-layered maze of barriers that compound each other, resulting in limited access to high quality care. The first layer and primary gatekeeper is insurance plan limitations, followed by home and community-based services to meet basic social needs, finding accessible clinics, and finally disability-competent providers. Across all focus groups, people with mobility disabilities and their providers reported that care coordination was a major facilitator in successfully navigating care across this complex, multi-layered system.

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Abbreviations

NYS	New York State
NYC	New York City
ICS	Independence Care System
WAVs	Wheelchair Accessible Vehicles
CDPAP	Consumer Directed Personal Assistance Program
FG	Focus Group

Background

Mobility disabilities, as defined by serious difficulty walking or climbing stairs,[1] are the most common disability type experienced in New York State (NYS). People with mobility disabilities represent 13.6% of adults in NYS, corresponding to an estimated 1.96 million individuals.[2] Multiple federal laws protect the right of people with mobility disabilities to receive equitable access to healthcare services. These laws include Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and the Affordable Care Act, Section 1557.[3-7]

Despite these protections, this population experiences persistent health and healthcare disparities. People with mobility disabilities have a 64% higher hazard of all-cause mortality when compared to those without these disabilities, even when holding other sociodemographic characteristics constant.[8] Among mobility, sensory, mental illness and cognitive disabilities, mobility disabilities have the strongest association with mortality.[8] People with mobility disabilities also experience significantly higher prevalence rate for seven chronic diseases.[9]

People with mobility disabilities report persistent disparities in receipt of high-quality, timely healthcare. For example, they are more likely to have unmet medical, dental and prescription needs.[9,10] Women with mobility disabilities are less likely to receive necessary, routine women's health care. For example, preventative services such as mammograms and Pap Smear tests are less likely to be current when compared to women without mobility disabilities.[11] Additionally, pregnant women with mobility disabilities report they are not routinely weighed during prenatal care visits,[12] despite routine monitoring of weight gain being a standard of maternal care.[13,14]

Evidence to date suggests that system-level access barriers impact receipt of high-quality healthcare. For example, people with disabilities are more likely to have health insurance coverage yet are still more likely to report cost-related barriers to healthcare.[15] They also commonly experience delays in receipt of essential mobility equipment.[16] Evidence is scarce documenting the system level barriers specific to NYS experienced by people with physical disabilities.

For all individuals, including people with disabilities, accessing healthcare is a fundamental part of living independently in the community. In 2013, The Olmstead Report identified specific strategies to assist people with disabilities to transition and thrive in community-based settings. This was a part of the Supreme Court decision in Olmstead v. L.C., 527 U.S. 581 (1999), which upheld "that the state's services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to a person's needs."[17] This report outlined programmatic investments in NYS health infrastructure to operationalize transitioning people with disabilities from segregated settings to the community.

Twelve years after The Olmstead Report, we have conducted this Needs Assessment to understand the experiences of accessing healthcare by people with mobility disabilities and the providers serving them. Furthermore, we report on the essential components within the NYS healthcare ecosystem for people with mobility disabilities to stay healthy.

Description of Participants

A total of 16 people with mobility disabilities participated in three focus groups and 8 participated in the provider focus group (Table 1). Over half of the people with mobility disabilities were between ages 40-59 and a handful younger than this. Just under half of this group was White and most were not Hispanic. Three-quarters of members were women. Half lived in New York City (NYC). The rest were spread across central NY, Long Island, and Hudson Valley. Of the people with

mobility disabilities that responded to insurance type (n=16), a range of insurance plans were represented, all of which were publicly funded, with the most common being managed long-term care plans. Finally, of the 16 members that provided their employment status, over half of were employed, either part or full-time.

In the provider focus group, nearly half were between ages 50 and 59. Almost all providers were White and not Hispanic. The majority of providers were women, and about half lived in NYC.

Table 1. Focus Group Participant Demographics

Age (years)	**People with mobility disabilities (n=16)**		**Provider (n=8)**	
	n	**%**	**n**	**%**
18-29	2	12.5%	0	0%
30-39	2	12.5%	1	12.5%
40-49	5	31.3%	2	25%
50-59	6	37.5%	3	37.5%
60-69	0	0%	1	12.5%
Missing	1	6.2%	1	12.5%
Race	**People with mobility disabilities (n=16)**		**Provider (n=8)**	
American Indian/Alaska Native	1	6.2%	0	0%
Black/African American	6	37.5%	0	0%
White	7	43.8%	7	87.5%
Other	2	12.5%	0	0%
Missing	0	0%	1	12.5%
Ethnicity	**People with mobility disabilities (n=16)**		**Provider (n=8)**	
Hispanic	2	12.5%	1	12.5%
Not Hispanic	13	81.3%	6	75%
Missing	1	6.2%	1	12.5%
Gender	**People with mobility disabilities (n=16)**		**Provider (n=8)**	
Male	4	25%	1	12.5%
Female	12	75%	6	75%
Non-Binary	0	0%	0	0%
Missing	0	0%	1	12.5%
Geographic Representation	**People with mobility disabilities (n=16)**		**Provider (n=8)**	
Central NY	3	18.8%	0	0%
Hudson Valley/Capital District	4	25%	1	12.5%
Long Island	1	6.2%	1	12.5%
New York City	8	50%	5	62.5%
Missing	0	0%	1	12.5%
Insurance [a, b]	**People with mobility disabilities (n=16)**			
Medicare or Medicare Advantage	3			18.8%
Medicaid	1			6.2%
Medicare and Straight Medicaid	2			12.5%

Managed Long-Term Care or Medicaid Managed Care	6	37.5%
Other	3	18.8%
Missing	0	0%
Employment[b]	**People with mobility disabilities (n=16)**	
Employed Full Time	6	37.5%
Employed Part Time	3	18.8%
Disabled/not able to work	6	37.5%
Not employed/looking for work	1	6.2%

a: Provider providers were not asked to provide responses in these categories.
b: Multiple selections per respondent allowed. Consequently, percentages do not sum to 100%.

Findings

Across focus groups, members described common experiences in navigating the healthcare system in New York within their respective roles as patients and providers. Ultimately, these experiences centered around layers of the system that acted as barriers to accessing high quality care. Provider participants consistently expressed experiences and insights that aligned with participants. Comprehensively, we describe these barriers as the multi-layered maze of accessing healthcare in NYS with a mobility disability (Figure 1).

Figure 1. Multi-Layered Maze of Accessing High Quality Healthcare

Figure 1. The four layers of navigating the New York State healthcare system as a person with a mobility disability: (1) insurance plan limitations, (2) basic social needs, (3) accessible clinics, and (4) disability-competent providers. The bottom layer is the result of navigating this maze. Participants described care coordination as a facilitator when navigating the healthcare system.

In the following sections, we describe the experiences of focus group participants organized by each barrier within the maze.

Layer 1: Insurance Plan Limitations as Main Gatekeeper

Members and providers commonly described insurance plan limitations as the greatest barrier to overcome. The limitations of insurance plan benefits played a role in accessing care at every step of accessing healthcare. Members reported that insurance benefit design and provider network adequacy trumped all else in limiting access to meeting basic social needs in home care, transportation, and mobility equipment, finding primary care and specialty care services located in accessible clinics, and accessing disability-competent providers. Providers corroborated members' experiences, although from the clinician seat. Providers frequently shared experiences where insurance plan benefits were misaligned with their own clinical recommendations to keep members with mobility disabilities healthy.

Finally, members underscored that due to the narrow range of care options available to them, these restrictions were highly consequential. A key example of this was a thread that repeatedly arose across all focus groups: accessing providers who understood their health condition and related disability. One patient participant who was a little person described her process of accessing podiatry. First, she said "it's not just any podiatrist, it would have to be a podiatrist that's familiar with little feet". She then described the process:

> *"When you find a provider that you're comfortable working with that understands or listens ... continuity of care is really important... the thing is, insurance networks...the navigating is really quite difficult...especially if we want [to] continue seeing the providers that we see, that understand us...that we've built a relationship with that, that now can pronounce the condition that we have and understand what our priorities are in terms of what we are looking for to be our best versions of ourselves...and so when you find those providers, then navigating, you know, the Medicare Advantage Plan networks and going through, okay, here are the, here are the drugs that I take, the pharmacies that I use, you know, which Medicare Advantage plan can work for me..." (Patient FG1)*

Layer 2: Meeting Basic Social Needs in Home Care, Transportation, and Mobility Equipment

Members reported that meeting basic social care needs was the fundamental first step to accessing healthcare services. To succeed at this, members delineated accessing **home care**, **reliable transportation** and **mobility equipment** as essential components.

In summary, participants said:

- **Home care:** Adequate home care often meant fighting for a sufficient number of service hours. Members experienced frequent challenges by insurance plans in obtaining this.

- **Transportation:** The main transportation options through Medicaid, non-emergent services and paratransit, were unreliable and interfered with meeting the demands of their personal and vocational lives.
- **Mobility equipment:** The insurance process required to obtain repairs to mobility equipment was unnecessarily intensive and protracted given the fundamental nature of this equipment in members' ability to access healthcare, their family and community activities, and overall well-being.

Home Care: Fighting for Sufficient Hours

Members with mobility disabilities reported that meeting basic social care needs was the fundamental first step to accessing healthcare services. While not typically thought of as a social need in the non-disabled population, members with physical disabilities highlighted this as a non-negotiable priority. They said that to meet basic self-care needs such as bathing, dressing, and transfers from bed to wheelchair, they were reliant on personal assistance programs.

Without this service, members said accessing healthcare was out of the question.

> *"First and foremost: home care. Everything else is secondary. I can't even go to an x-ray or a doctor's appointment without getting outta bed, you know?" (Patient FG1)*

Another participant said:

> *"Once that's [home care] in place, then everything else has the possibility of aligning properly." (Patient FG1)*

Despite the core nature of this need, many members said that insurance providers often denied their requested number of home care hours. They described lengthy processes where they needed to defend their home care hours to complete self-care tasks.

Two poignant examples of this came from members who were mothers to young children. They shared their experiences in being denied home care hours by their insurer. These mothers reported their insurance companies assumed their children were adults and expected the children to provide homecare.

> *"When I say 'my daughter', I don't know why, there's always an assumption that she's an adult. So I have to remind people she is eight years of age, so what I need help with, she is not responsible for, thank you. And they [insurance provider], in my experience that is always used to see if they can reduce home care hours at any cost." (Patient FG3)*

> *"With them [insurance provider] saying, you are not going to be approved for weekends because you live with two other people. First of all, those two other people, I'm their caregiver. They're not supposed to be mine." (Patient FG3)*

Participants also said that regional factors affected access to personal assistance services. Outside of New York City, participants reported personal assistants can be hard to find. They said this was potentially due to needing to drive farther distances for short service periods.

From the Providers

In the provider group, the focus group questions primarily addressed direct healthcare access, however providers independently emphasized the importance of home care in keeping their patients with disabilities healthy. Their comments corroborated that insurance plans often provided a smaller allowance in home care hours than members needed to meet basic self-care needs.

> *"A couple things, we just didn't talk about where things where insurance, particularly Medicaid, interferes when we're talking about people with disabilities trying to live independently, where home care and home care hours are very important for them to be able to stay and live in the community and do the things that they're needing." (Provider FG 1)*

Transportation: Current Options Are Time Consuming and Unreliable

After home care services and being able to complete basic self-care, members underscored adequate transportation services as critical to accessing their medical care.

> *" After getting outta bed, then I need Medicaid-funded transportation services to get to that doctor." (Patient FG1)*

However, there were complications in finding reliable and accessible transportation. The participants described the Medicaid non-emergent medical transportation rideshare services as unreliable related to the duration of each trip. This resulted in either arriving too late or hours before their scheduled appointments. Also, they often needed to wait a substantial amount of time for pick up. This service utilizes a rideshare structure where multiple individuals are scheduled on the same ride. They described it being difficult to plan their day as ride times varied depending on the locations of where other riders lived. Sometimes a single medical appointment consumed most of a potentially productive day.

> *"You're picking everybody up and you're taking the tour of the city and there's no time on that. And that is not comfortable when you come from your appointment, you're tired from that anyway. And then to have to take a journey touring New York City, that is not helpful." (Patient FG3)*

Participants also described coordinating the rideshare service as another layer limiting access to their appointments. Medicaid rideshare bookings typically require at least two to three days advance notice. This meant that changes in a reserved ride service required doctor's note, which required another layer of coordination with their doctor's office.

Ultimately, these aspects of the Medicaid transportation service were limiting factors in their ability to have an active life and day-to-day commitments such as parenting or maintaining a job. For this reason, members that had the means found other modes of accessible transportation. One participant paid friends to drive him to appointments. Others used the E-Hail services which contracts with Lyft and Uber and allows greater flexibility in transportation coordination. Private rideshare companies also offer services with Wheelchair-Accessible Vehicles (WAVs) that people with mobility disabilities can leverage. Members who could afford these services were largely satisfied with these services, as they were reliable and allowed them to control their schedule in ways that the rideshare cannot.

“Most currently, which has been very helpful if you live within the five boroughs, the Access-A-Ride eHail program has been Godsend, so I'm using them as a format to get to work and to get to my doctor's appointments.” (Patient FG 1)

Despite this, members also pointed out that private rideshare options were not affordable by all.

“If you are an individual with a disability who needs to go to dialysis three to four times a week if you live on a fixed income that can get a low costly so then you result into having to use their transportation, which is covered by the Medicaid service.” (Patient FG 1)

From the Providers

Providers also expressed a keen recognition of the transportation barriers that members with mobility disabilities experience to get to their medical appointments.

"I'm thinking of a patient I saw this morning who does not live in the city. Just accessing certain services like physical therapy or follow-up, you know, for an MRI becomes a challenge just from a distance point of view, and then relying on his partner to drive him in for appointments. And so there's just some very practical limitations...distance and accessibility... if you're relying on Access-A-Ride for everything, I mean, that's eating up a huge portion of your day." (Provider FG 1)

Mobility Equipment: Protracted Repairs Impact Well-being

Multiple members described experiences of being severely restricted in accessing healthcare, life and overall well-being related to protracted wheelchair repair experiences. They emphasized that mobility equipment was how they got around in their homes and community and thus protracted repairs fundamentally impacted their ability to access healthcare, in addition to completing basic self-care, family, and community activities that led to overall well-being.

"That's like telling someone, you know, just freeze, don't walk, like, just freeze in place because without my chair I can't go to work. I can't take care of my kids." (Patient FG 2)

Multiple members said they felt a lack of appreciation for the fundamental role that wheelchairs played in their lives. They said that simple wheelchair repairs were often an unnecessarily complicated and protracted process. One participant provided this example:

"So, if my wheelchair breaks, then I have to go to a doctor to get a referral, but I have to wait for an appointment for that doctor which is not right away. So you have to wait, I have to wait at least four weeks to six weeks to see a doctor to then get a referral for repair, to then get evaluated by a facility...a place that fixes wheelchairs. And then they do an evaluation and then they tell you what equipment you need. You then go back to the doctor to get another prescription on what you need. You then go back with that prescription, you know, then you have another. You know, if the nurse doesn't get back to you from that doctor, you have yet another appointment you have to go to. It's just several appointments. By the time my chair gets fixed you know, it's like five months later, six months later."

Finally, many members said that lacking the ability to mobilize outside of a room or home for months on end negatively affected their mental health. Going through the wheelchair maintenance process left them isolated at home and unable to meet the demands of their daily lives.

"It end[s] up affecting your whole life. You can have something wrong with your foot plate on your wheelchair, and it's going to take them two months to fix it. You can't go out anywhere. Now you are in the house depressed, and you know, you can't go to the doctor." (Patient FG3)

One participant made the point that the repair process was so reliably long that rather than being without a wheelchair, she would try to get by with makeshift repairs of her equipment herself. This posed a safety risk which she acknowledged, but she preferred this risk over going through the wheelchair repair process. However, she was frustrated to be in this situation needing to choose between being immobilized while waiting for a wheelchair repair and maintaining access to her wheelchair while putting her safety at risk. Members also said that loaner equipment was inconsistently available. They pointed out even when available, this equipment was only a short-term option as it was not fitted to their bodies, often causing inefficient mobility, discomfort and pain over time.

From the Providers

Across home care, transportation and mobility equipment services, clinicians shared frustrating experiences in their role prescribing clinically appropriate services.

"In looking both at medications and things like wheelchairs and equipment, and home care hours and services like that, it is the insurance telling us, no, no, no, 'you want this, but you can't have it even though you are the clinician.'" (Provider FG 1)

They expressed insurance denials as directly impeding their ability to use their clinical judgment. One way that insurance denied clinical recommendations for mobility equipment was to "downcode" or approve a cheaper option reimbursed at a lower rate.

"Whereas now the insurance will automatically, deny or downcode. And, if you downcode, then you have to, you know, is the vendor willing to provide equipment that they're not gonna get wholly reimbursed for? … I do feel that our hands are tied a little bit in terms of what we can provide for a wheelchair, bath equipment, a standing frame, you know, stuff that we have to really either not be able to provide or provide very sparingly as compared to previously." (Provider FG 1)

Insurance denials are so common and pervasive providers described needing to choose between prescribing clinically recommended equipment at the high risk of delays in acquiring the equipment due to the vendor refusing to fill the script; or pre-emptively downcoding to match the anticipated insurance option. The latter minimized potential delays related to back-and-forth paperwork, but the patient misses the opportunity to use the equipment best suited for them. Providers felt disheartened by these two choices, neither of which fulfilled their goal of providing the highest quality care to their patients.

"I just felt like I already adapted my clinical decision making and what I would order for patients based on how hard I knew it would be to get that thing. So I'm already changing my behavior even upstream of trying to get the service and that I'm making judgment calls on whether it's worth the effort to try to get the thing. … I knew it would send me down a rabbit hole, like four hours trying to figure out how to do something that I didn't have time for." (Provider FG 1)

Layers 3 & 4: Accessible Clinics and Disability-Competent Providers

Members and providers described a limited pool of accessible clinics and disability-competent providers. When geographic limitations of insurance plans overlaid upon these limited choices, members were left with few to no choices. Members underscored provider network limitations as a significant barrier to finding disability-competent providers located in accessible clinics.

One member highly knowledgeable about insurance plan limitations in her role as a certified patient advocate and Medicare counselor said that the limited network was the primary reason she stayed with traditional fee-for-service Medicare and Medicaid rather than a managed long term care plan. She said that she was able to access providers knowledgeable on her condition through staying in the traditional Medicare and Medicaid option. While this came with an added layer of navigating two separate insurance benefit plans, she said it was a mild tradeoff for the benefit of accessing providers knowledgeable about her condition.

> *"So what I'm saying is it's not as complex as the myth that it is when you have original Medicare and you have Medicaid…I just wanna make sure we're on the same page with understanding that, for people with physical disabilities, it is so important for us to maintain our providers." (Patient FG 1)*

Layer 3: Accessible Clinics

Accessible clinics encompassed being able to get into their doctor's office as well as available exam equipment enabling them to participate fully in standard exams. Participants described a lack of exam equipment that they could safely transfer to or that could accommodate their wheelchair.

> *"I'm always afraid of getting hurt by somebody physically lifting me. They don't have Hoyer lifts. There's a very large healthcare provider in my county and outside of it as well. They don't even allow me to bring my own lift in. They can't help and none of their workers can physically help me." (Patient FG 1)*

Two women said finding accessible women's healthcare is a problem. However, they noted they were fortunate to have good care coordinators enabling them success in identifying accessible clinics.

> *"When it comes to mammogram and GYN I do use my coordinator through ICS, so we can go to an accessible location, which is geared for wheelchair users…which is very, very helpful." (Patient FG 3)*

> *"During my pregnancy, they [care coordinators] were very, pivotal in making sure that I had a wheelchair accessible birthing room, which I'm pretty sure most women in general – with or without disabilities – don't even realize that that exists." (Patient FG 3)*

Layer 4: Disability-Competent Providers

Another layer identified by both members and providers related to disability-competent providers. Members said this competence encompassed both having knowledge about disability-related health issues and respecting the expertise that patients with disabilities have about their own bodies. For example, one member with spina bifida said she could only find specialists who saw pediatric patients.

> *"In my experience [it] has been challenging in the sense of finding doctors that specialize in care for adults with spina bifida. Apparently there a lot of doctors that specialize in pediatric care for spina bifida, but not adults." (Patient FG 2)*

Members emphasized the importance of their doctors respecting their experiences and narratives of their medical symptoms.

> *"I think for me it comes down to medically competent doctors…Medically competent doctors who are, who also have good bedside manner and are willing to listen to me and understand that they may be experts in medicine, but I'm expert in my own body and my own experiences." (Patient FG 2)*

Additionally, due to the challenges of navigating insurance and accessible clinics, members and providers said experience with navigating the NYS health system related to insurance benefit limitations, accessible clinics and other knowledgeable providers was key.

> *"It funnels down even further of people who have the capacity and the knowledge and expertise to treat people with physical disabilities. In addition to the accessibility of it as well is, 'Are the resources that are out there, are they fully accessible for somebody who may be a wheelchair user has mobility?', so it's already limited. Then it even drills down even less when they might have expertise." (Provider FG 1)*

One primary care provider who no longer primarily serves people with disabilities, acknowledged how difficult this navigation expertise was to attain.

> *"The one other thing that comes to mind for me is, honestly looking at you all, I think as people who are really expert at navigating the system, and again, I think of when I was at [redacted], I felt really inexpert, like, had a hard time navigating it as a primary care provider." (Provider FG 1)*

> *"And one of the things that really stuck with me was that building relationships with the right providers or the right services right people was so important. And you do that over years of like really building out those relationships and knowing where to send your members. I always had wondered, is there a way to make that feel more sustainable? … That, it's easier to find. Providers or places that are disability friendly, or that I can send my members to and I know what to expect, they know what to expect." (Provider FG 1)*

Compounding members' ability to identify accessible clinics was geographic limitations. Members said that regional limitations written into insurance plan designs were major barriers to disability-competent specialty service providers. Members who reported the greatest difficulties lived outside of the city. They reported few disability-competent specialists in their geographic areas. To

access these specialists, members again needed to complete burdensome administrative paperwork.

> *"So a lot of times, you know, distance could be an issue, and everyone always has tried to get me to see someone closer, but the folks that are closer to me are not knowledgeable about disabilities. So it's kind of like being forced to go outside of your geographic area to make sure that you get the proper care." (Pt FG1)*

Members said that even after gaining approval to see a disability-competent provider outside of their geographic area, transportation was another limiting factor. Transportation services set their own geographic boundaries. Members described needing to complete yet another layer of administrative paperwork to gain an exception.

> *"Recently, it's come to my understanding that if you now live say in Brooklyn and your doctor is in Queens, there is a separate form that needs to be completed because they prefer, for you to utilize a physician or specialist within the borough that you live in. And realistically speaking, we all know that sometimes we [people with disabilities] gotta go outside of what we know to get the right care." (Patient FG 1)*

Due to multiple past negative experiences with providers, members prioritized disability competence over geographic convenience. Once they found a disability-competent provider, they remained loyal regardless of location.

The Result: Deferred Care, Lower Quality Care, and Unmet Care Needs

The compounding nature of these four barriers resulted in a cumulative burden on members, care partners, and healthcare providers. Both members and providers conveyed a sense of fatigue and exhaustion related to the constant fight required to obtain sufficient medical care that met the healthcare needs of people with mobility disabilities.

> *"All of these battles are so emotionally exhausting that you pick your battles according to your, the hierarchy of life." (Patient FG 2)*

One patient provided an example of a lack of provider knowledge potentially affecting safe treatment options. She shared how a surgeon recommended surgery despite her not having sufficient home care hours to complete the requisite post-op care. She gave this as an example of doctors failing to take disability access factors into account in their treatment recommendations.

> *"I talked to one of the surgeons and I said, well, listen, I only get this many hours of home care and if I get this surgery, I'm gonna need this many hours of home care, can you help me with that paperwork, you know, to get that in place? Because otherwise that could be really detrimental. I mean, I'll get the surgery, but I can't clean the wound or take a shower, you know?" (Patient FG 1)*

Members said that when they had clinicians who were not disability-competent, they needed to spend medical visit time providing education on their disability and potential medical implications

of their complex care needs. This affects the quality of their medical care as they aren't able to spend the same amount of time focusing on their health concern.

> *"It takes 20, 15 to 20 minutes for me to do the education to any new provider anyway. And then by that time we didn't even get to the issue that I came for." (Patient FG1)*

Most of the members were in very active years of their life. Thus, the toll of navigating the layers of healthcare access competed with meeting basic family and work duties. This resulted in deprioritizing routine care and rationing medical care.

> *"That's like couple hours outta your day, including seeing the doctor. And that's assuming the doctor's running on time, which frequently they are not because they have too many members [with disabilities], because in a small city like Albany, .. there's not very many options. And so if you are somebody who, or anyone really, you have other things you have to worry about in life. You have to worry about your family, you have to worry about work, you have to worry about you know, living. I mean, you can only spend so many days doing that [attending medical appointments]. So sometimes it's like, okay, well maybe I just go to this doctor, this doctor, and not all of them" (Patient FG 2)*

From the Providers

Providers corroborated that their patients with disabilities seem to pick and choose which appointments they attend due to limited time and energy resources. They said that this occurred due to the fatigue, sheer number of appointments, and the lack of consistency with primary care provider disability knowledge. As a result, preventive care appointments, screenings and services typically done with primary care were deprioritized.

> *"I think it also becomes, like just there's a fatigue, right? There's a fatigue of following up, like ... it's like just, it's kinda like red light, yellow light, green light. What is my biggest problem right now and how can I triage it?" (Patient FG 2)*

Another provider added that the lack of disability-competent providers in the primary care space added to this problem. Members then over-relied on their MS specialists because of their knowledge about their disability-related health needs.

> *"And ... if there's active issues in one area and they're showing up at the MS center. When I say, when was the last time you saw your primary care doctor? And it's like: 'There's nothing going on for me to talk about with them'..." (Provider FG 1)*

> *"A lot of times there's a real comfort level with seeing certain specialists, like as an MS provider, right. And it's like they'll, I'll often for the last 25 years, I hear people say, well, you know, I need a primary care provider who knows MS. I need a gynecologist who knows MS...Because there's this deep desire to connect with someone who gets them." (Provider FG 1)*

Providers also described how the multi-layered factors affected the quality of care they were able to provide. One provider shared that at times insurance limitations dictated her clinical treatment options for people with disabilities.

"Often, it's not the providers who are making the decision about what the treatment should be. It is the insurance…So even though I believe that this is the right thing for this person, the insurance can come back and say, no, you actually can't do that." (Provider FG 1)

Expanding upon the sentiment that arose during the wheelchair prescribing discussion, providers described that in general, after numerous denials, they started making clinical decisions and recommendations based on what they think insurance companies will pay for. The cost of multiple denials is the time spent navigating back-and-forth paperwork and processes. One provider who previously practiced in New York and served a primary disabled population, described this as a reluctant reality:

"When I was in New York, I was at [redacted] Hospital and there I just felt like I already adapted my clinical decision making and like what I would order for members based on how hard I knew it would be to get that thing." (Provider FG 1)

Similar to members, providers also conveyed a sense of fatigue with navigating the healthcare system. One provider said that the increasing transition to long-term managed care services has only exacerbated this fatigue.

"There's more rules. So it's not just a script. Now it's, they need medical chart notes. It's not just medical chart notes. They need a letter of justification. And so for busy providers there's a higher demand of what we need from them, and then there's follow up so that then fatigue happens to these folks in a level of frustration because they're just, those layers are roadblocks …" (Provider FG 1)

This provider emphasized that these added layers of administrative burden ultimately led to decreased access to essential medical care equipment that members need to stay healthy.

"So then those roadblocks just are frustration, and that leads to them not getting, this isn't about getting something that's a nice to have. It's about getting something that is a need to have to live safely every day like a catheter or medication or a piece of equipment that allows me to take a shower." (Provider FG 1)

Care Coordination

Across all focus groups, when members and providers brought up bright spots in their journey navigating healthcare, their experiences centered around care coordination. Participants consistently identified these services as a key facilitator in navigating the multi-layered maze of healthcare. Care coordination services are wide-ranging and can include any activities managing, organizing, and explaining patients' rights and available services.

Care coordinators can be employed by health insurers, can be a part of third-party organizational support networks, or can be more episodic and connected to provider clinics. Members said that coordinators provided services that substantially relieved the burden of care navigation. These included helping them understand insurance benefits and coverage of services, being knowledgeable about their health needs related to their disability, identifying accessible clinics and knowledgeable providers, scheduling appointments and ensuring appropriate accommodations at medical appointments, and successfully submitting appeals for rejected claims. For example, the

member whose insurance plan presumed her kids were adults who could provide care services to her, attributed her understanding of her rights and obtaining the appropriate number of hours, to her care coordinator.

Health care providers equally recognized care coordinators as essential to acquiring services needed to keep their members healthy. Part of this was that the expertise in navigating healthcare was beyond their scope of knowledge.

> *"If they don't have that family support or a caregiver who has the capacity to help, then they need that kind of care management – that access to navigate a very complicated system because it's complicated – it's complicated for anybody." (Provider FG 1)*

However, members reported that not all care coordinators were created equal. First, many care coordination services were provided as a part of an insurance plan and structured so that assistance was a "checklist" of services recommended and covered by that plan. Members described this checklist as unresponsive to their specific needs. Members whose care coordinators took this approach said these coordinators also had limited knowledge of disability needs, accessible clinics and providers. Members who had these types of coordinators expressed dissatisfaction with their services.

> *"...if you need certain services that you're talking to your care manager about, you know, they're only focused on particular things within the particular unit of the thing that they have to do, and so they have to, I hate to say it, but check the boxes of what they need to do." (Patient FG 2)*

However, participants also shared positive examples of when care coordinators were knowledgeable on disability health, accessible services. This resulted in success stories of

accessing the right care at the right time and feeling like their needs were being met. For example, multiple members stated Independence Care System as an example of a highly effective care coordination service.

> *"Definitely ICS has been a staple in my life as far as care coordination and what [redacted] definitely said. ICS is that one stop shop...At that one time, ICS will navigate you in a way where you need to speak to your care navigator. You need to speak to this person, or you have the care navigators that, well, let's – let's get on a call together and make this call to your PCP or your physiatrist. And it gets done. And in that way, let me use the word, I'm spoiled in that way. I'm spoiled. But anybody receiving healthcare should be spoiled in that way, where you get directed to the right particular individual or group that will address your needs to get in things done so you don't have to wait in the system forever." (Patient FG 2)*

Discussion

This Needs Assessment revealed a complex, multi-layered system of healthcare access barriers facing people with mobility disabilities in New York State. These layers create a maze of limitations for members trying to access healthcare: (1) insurance plan limitations; (2) services to meet basic social needs; (3) scarce accessible clinics; and (4) few disability-competent providers.

Across these layers, members and providers described heavy administrative burdens and resultant fatigue. These compounding barriers resulted in members rationing medical care, deferring

preventive services, and experiencing lower quality care. Participants described "picking and choosing" medical appointments based on a "hierarchy of life," acknowledging that while all services were important, the burdens of accessing healthcare competed with family and work responsibilities. Care coordination emerged as a critical facilitator, however like providers, participants noted significant variability in disability competency of their care coordinators.

These findings align with prior literature at national and state levels. At a national level, Karpman et al.'s 2024 report "Insights from Nonelderly Adults with Disabilities on Difficulties Obtaining Home- and Community-Based Services and Other Health Care" similarly documented compounding barriers across multiple healthcare domains for adults with disabilities in the working age range. Karpman et al. cited insurance barriers as a main factor limiting care for people with disabilities, consistent with this Needs Assessment findings.[18] In meeting basic social needs, Karpman et al. identified that 1 in 20 reported not receiving needed home care services, and nearly 1 in 5 reported delaying or not receiving needed medical equipment.[18]

Also at a national level, increased likelihood of delaying or forgoing care among people with disabilities is well-documented.[9-11] The findings from this needs assessment flesh out potential reasons for this in NYS. Our findings suggest these four primary limitations in accessing healthcare contribute to poorer outcomes for people with mobility disabilities. In addition to insurance plan limitations and not being able to meet basic social needs, participants reported a narrowed pool of accessible clinics and providers. These findings on the narrowed pool of accessible clinics and providers in NYS are also consistent with national evidence. [18-22]

This is the first evaluation documenting the experiences navigating healthcare for people with physical disabilities in NYS that we could identify. However in neighboring Massachusetts, through its Department of Public Health and in partnership with the UMass Center for Health Policy and Research, a statewide needs assessment was conducted in 2014.[23] Their focus group findings also highlight insurance coverage as a primary limiter in healthcare access. One of their participants said that people with disabilities "are always having to gamble on their health" because they are "having to battle the bureaucracy for the coverage".[23]

Increasing the number of accessible clinics and disability-competent providers is a straightforward, long-term solution to address root causes. Until then, short-term solutions exist. Health plans could allow people with mobility disabilities exceptions to go out of network, expand provider networks to include providers who already have knowledge on disability health, and reduce administrative burdens are feasible solutions. Additionally, plans could develop a standardization method for disability-competent providers and identifying them for members in a directory format.

Multiple participants in Medicaid Managed Long Term Care reported insufficient provider networks, particularly limiting access to disability-competent specialists. This aligns with evidence in Kansas, when patients with disabilities were unable to access their disability-competent providers after moving to managed long term care plans.[24] Our findings indicate that people with mobility disabilities are also experiencing this in NYS. This goes against NYS Public Health Law § 4403-f requiring managed long term care plans to ensure "availability and accessibility" of services and maintain continuity of care.[25] Our findings suggest that executing this law requires special consideration for people with mobility disabilities. Network adequacy standards should recognize that geographic proximity is insufficient in the current context of few accessible facilities and disability competent providers in the state. Given these current conditions, managed care plans may need enhanced network requirements and monitoring to prevent access restrictions that could compromise healthcare access for people with mobility disabilities.

Finally, care coordination was cited as a highly effective solution to navigating and accessing high-quality healthcare. However, members said that a coordinator's effectiveness depended on their

quality. Care coordinators, like healthcare providers, also need to have disability competence. Currently there are no standards in knowledge levels for coordinators working with people with disabilities. However, bright spots exist. Members and providers named Independence Care System as an example of a high-quality care coordination service they had experienced.

Recommendations

Members identified principles in program design and bright spots during their healthcare navigation process. Below are those principles and examples of successful programs which have made achieving health successful for them.

Table 2. Examples of Successful Programs

	Program design principles	Bright spots or Suggested Examples, if mentioned
Insurance Plan Design	**Expand provider networks** with sufficient access to clinics and providers with adequate disability accommodations. **Design plan flexibility enabling receipt of care out of network and geographic boundaries** to address the current shortage of disability-competent providers.	• Traditional Medicare and Medicaid.
	Mitigate administrative processes related to getting disability needs met. This will increase efficiency and reduce member fatigue.	
Services Addressing Basic Social Needs (Self-care, transportation, mobilization)	Program design which supports **control and planning within one's own schedule**.	• **E-Hail Pilot Program**: E-Hail is a part of Access-A-Ride that has piloted offering on-demand transportation services. E-Hail has established a partnership between Access-A-Ride and private transportation companies to allow customers to use transportation services on short notice. The Metropolitan Transportation Authority subsidizes the cost to offer affordable, reliable transportation options to people with mobility disabilities. • **Consumer Directed Personal Assistance Program (CDPAP)**: CDPAP is a Medicaid program that allows individuals to have autonomy in selecting home health services. It offers a safe, at-home option for members requiring skilled needs because it allows for needs to be met at-home needs instead of in a facility. Within the program, members are able to select and hire a personal caregiver to provide support at home and control when personal assistance aids arrive. One patient participant who was in school emphasized

		how critical this was in allowing her to attend her classes.
Accessible Clinics and Disability-Competent Providers	**Incentives** to motivate clinics to invest in accessible equipment and overall physical access. **Incentives** for providers to gain disability competent knowledge. **Disability-competent standards** for providers. A **directory** of disability-competent and accessible clinics.	• Living in the city improved access to care • Support a way to identify or certify disability competence services • Until the number of accessible clinics and disability competent providers increases, participants said a **directory of accessible clinics and disability-competent providers** would be extremely helpful.
	Cross-disciplinary clinics with primary care and disability specific care (e.g. wheelchair clinic) in one location.	• **Primary care co-located with multiple sclerosis specialists**, or with a wheelchair clinic.
Care Coordination Services	**More disability-competent care coordination services.** High quality means having a holistic understanding of disability health needs *and* knowledge of the nuances of navigating the complex NYS public healthcare system, including the network of existing accessible clinics and disability competent providers. **Care coordinators employed independent of insurance companies to support unbiased navigation for people with disabilities.** Healthcare services for people with disabilities often have higher upfront costs. Care coordinators employed by insurance plans are thus disincentivized to offer these services.	• **Independence Care System (ICS) Care Coordination services**: ICS offers holistic care coordination support for its members. Focus group participants highlighted ICS care managers as highly knowledgeable specific to their disability needs, experienced, professional, effective, and committed to patient's success. • An incentive program **motivating successful connection of members to needed resources**.

Conclusion

Evaluating these findings in the context of The Olmstead Report reveals that substantial work remains to achieve accessible healthcare services for New Yorkers with mobility disabilities. However, the needs are clear and mirror prior evidence across the nation. Importantly, there are highly pragmatic and concrete actions that health plans and policymakers can implement immediately to make health and healthcare accessible for people with mobility disabilities, ultimately fulfilling New York State's commitment to full community integration for this population.

References

1. U.S. Census Bureau. How Disability Data are Collected from The American Community Survey. October 6, 2024,. https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html
2. New York State Department of Health. *NYS BRFSS Brief*. 2023. https://www.health.ny.gov/statistics/brfss/reports/docs/2023-02_brfss_disability_status.pdf
3. US Department of Justice Civil Rights Division. Americans with Disabilities Act of 1990, as Amended. . Accessed April 27, 2019, https://www.ada.gov/effective-comm.htm
4. US Department of Justice Civil Rights Division. ADA Requirements: Effective Communication. Accessed May 24,, 2023. https://www.ada.gov/resources/effective-communication/
5. Affordable Care Act. In: Department of Health and Human Services: Office for Civil Rights, editor. 2010.
6. US Department of Health and Human Services. Section 1557: Ensuring Effective Communication with and Accessibility for Individuals with Disabilities. Accessed March 30, 2023. https://www.hhs.gov/civil-rights/for-individuals/section-1557/fs-disability/index.html
7. U.S. Department of Health & Human Services: Office for Civil Rights. Section 504 of the Rehabilitation Act of 1973,. n.d.
8. Forman-Hoffman VL, Ault KL, Anderson WL, et al. Disability Status, Mortality, and Leading Causes of Death in the United States Community Population. *Medical Care*. 2015;53(4):346-354. doi:10.1097/mlr.0000000000000321
9. Reichard A, Stolzle H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and health journal*. 2011;4(2):59-67.
10. Mahmoudi E, Meade MA. Disparities in access to health care among adults with physical disabilities: analysis of a representative national sample for a ten-year period. *Disability and health journal*. 2015;8(2):182-190.
11. Krahn GL, Walker DK, Correa-De-Araujo R. Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*. 2015/04/01 2015;105(S2):S198-S206. doi:10.2105/AJPH.2014.302182
12. Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Physical Accessibility of Routine Prenatal Care for Women with Mobility Disability. *Journal of Women's Health*. 2015/12/01 2015;24(12):1006-1012. doi:10.1089/jwh.2015.5385
13. Wang L, Zhang X, Chen T, et al. Association of Gestational Weight Gain With Infant Morbidity and Mortality in the United States. *JAMA Network Open*. 2021;4(12):e2141498-e2141498. doi:10.1001/jamanetworkopen.2021.41498
14. The American College of Obstetricians and Gynecologists: Committee on Obstetric Practice. Weight Gain During Pregnancy 2. ACOG Committee Opinion2013.
15. Hanson KW, Neuman P, Dutwin D, Kasper JD. Uncovering The Health Challenges Facing People With Disabilities: The Role Of Health Insurance: Findings from a 2003 national survey of people with disabilities highlight barriers to care among the uninsured and those with gaps in coverage. *Health Affairs*. 2003;22(Suppl1):W3-552-W3-565.
16. Karpman M, Morriss S, Gonzalez D. Barriers to Accessing Medical Equipment and Other Health Services and Supports within Households of Adults with Disabilities. *Policy Commons Urban Institute, Washington, DC*. 2024;
17. Cuomo Andrew and the Special Counsel for Olmstead. *Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving People with Disabilities in the Most Integrated Setting*. 2013.
18. Karpman M, Haley JM, Gonzalez D, Morriss S, Evans C. Insights from Nonelderly Adults with Disabilities on Difficulties Obtaining Home-and Community-Based Services and Other Health Care. 2024;

19. Agaronnik ND, Pendo E, Campbell EG, Ressalam J, Iezzoni LI. Knowledge Of Practicing Physicians About Their Legal Obligations When Caring For Patients With Disability. *Health affairs (Project Hope)*. Apr 2019;38(4):545-553. doi:10.1377/hlthaff.2018.05060
20. Iezzoni LI, McKee MM, Meade MA, Morris MA, Pendo E. Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care? *Health Affairs*. 2022/10/01 2022;41(10):1371-1378. doi:10.1377/hlthaff.2022.00413
21. Iezzoni LI, Rao SR, Ressalam J, et al. US Physicians' Knowledge About The Americans With Disabilities Act And Accommodation Of Patients With Disability: Study examines what physicians know about the Americans With Disabilities Act and what is done to accommodate patients with a disability. *Health Affairs*. 2022;41(1):96-104.
22. Lagu T, Haywood C, Reimold K, Dejong C, Walker Sterling R, Iezzoni LI. 'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities. *Health Affairs*. 2022;41(10):1387-1395. doi:10.1377/hlthaff.2022.00475
23. Mitra M, Clifford CJ, Smith MLD, Landers B, Tanenhaus R, May GS. Health needs assessment of people with disabilities in Massachusetts, 2013. https://www.mass.gov/files/documents/2016/07/xj/needs-assessment-report-for-health-and-disability.pdf#page=67.12
24. Hall JP, Kurth NK, Chapman SLC, Shireman TI. Medicaid managed care: Issues for beneficiaries with disabilities. *Disability and Health Journal*. 2015/01/01/ 2015;8(1):130-135. doi:https://doi.org/10.1016/j.dhjo.2014.08.010
25. New York State Senate. Public Health Law § 4403-f: Managed long term care plans. . Accessed May 27, 2025. https://www.nysenate.gov/legislation/laws/PBH/4403-F
26. Inc. ZVC. https://zoom.us/

Appendix A: Methods

Design and Sample

This Needs Assessment was initiated by the Independence Care System (ICS), a non-profit based in New York City that operates a Medicaid managed long-term care plan that is the first and only Health Home dedicated to people with physical disabilities in NYS. Its mission is specifically designed to support adults with physical disabilities and older adults achieve independence and remain active members of their communities. ICS led the project objectives and contracted with two Needs Assessment researchers (JO and KE) to conduct the Assessment. This assessment included conducting focus groups, analyzing the data, and writing the report findings.

The two project researchers conducted semi-structured focus groups with a total of four groups. Three of the focus groups were with people with mobility disabilities and one focus group was with providers caring for people with mobility disabilities. The semi-structured format allowed facilitators to follow the flow of discussion directed by group participants, probe deeper, expand, and obtain clarification when appropriate.

Snowball sampling was used to recruit participants. Sampling began within the Independence Care System (ICS) network of members and expanded to affiliated organizations, professional contacts, and community advocacy groups. Participants were compensated $50 for participation.

Data Collection and Analysis

Each focus group lasted between 1-1.5 hours. They were conducted over Zoom[26] between December 17, 2024 and April 6, 2025 and consisted of between 5 and 8 participants. The researchers worked with the ICS team to develop a question guide explicating the two-pronged exploration of 1) the experiences of people with mobility disabilities accessing and navigating the healthcare system and 2) factors they prioritized in keeping them healthy (Appendix B). The overarching project question was addressed through the domains of care coordination, health-related social needs, primary and preventive care, and quality assurance. Following each focus group, the researchers completed summary forms which condensed information heard, surprising topics and content, topics and content emphasized by participants, identified themes or issues worthwhile of following up, and any needed improvements in the question guide. All focus groups were recorded and transcribed.

The researchers utilized a rapid matrix qualitative approach to analyze the transcribed data and notes in summary documents. The matrix domains were identified and defined after reviewing the summary documents and transcriptions. Once the matrix was created, researchers double-coded (assigned domains) 2 of the 4 focus group transcriptions. Through this process, clarifications were made in definitions and understandings of the code domains. Following this stabilizing process of the domain codes, the remaining two transcripts were single-coded.

Completed matrices were then reviewed for recurring ideas, similarities, points of contrast and emphasis by participants and patterns within and across domains. Through iterative review and team discussion, codes were synthesized and emerging themes clarified to arrive at final themes.

Study Limitations

This needs assessment was commissioned by Independence Care System (ICS) to examine healthcare access experiences for people with mobility disabilities in New York. The intent behind

the assessment was not for this to be generalizable knowledge, but specific to many of the members with mobility disabilities served by ICS and in NYS public insurance programs. While ICS provided funding for this study, the research team conducted the interviews and analysis independently.

Participants were informed of voluntary participation with confidentiality protections and were encouraged to share honest experiences. The study included both people with mobility disabilities and healthcare providers to capture multiple perspectives. The focus group participants were recruited through specific networks and may not represent the full diversity of people with physical disabilities. There may be self-selection bias toward those with particularly strong healthcare experiences either in the positive or negative direction. As a qualitative study, findings provide in-depth insights but do not quantify prevalence of challenges across the broader disability population. Despite these limitations, the consistency of themes across multiple focus groups with both patients and providers strengthens the credibility of findings, and the detailed participant quotes provide authentic voices that illuminate the lived experiences of navigating the NYS healthcare system with a mobility disability.

Appendix B: Question Guides

People with Mobility Disabilities Focus Group

Introductory Questions

1. What components of your health and social care are most important to you? In other words, the top services which allow you to lead a fully inclusive, healthy life?
2. What are the components of the care that you receive that most need improving?
3. Are there services and support that you need that are not adequately provided?

Care Coordination

4. How do you coordinate your care?
5. Do you primarily coordinate your care yourself or are there individuals who assist you?
    a. If you coordinate care on your own or through a family member, why do you prefer this over using a coordinator provided by your health plan?
6. In its current state, how well is your coordination of your care going?
7. How do these services affect your health?
8. How important is your care manager in accessing the care and services you need to remain healthy and independent in the community?
9. Can you give an example of a time when your care manager helped you?
10. Who do you rely on to get the services (e.g. home care, medical equipment, supplies) you need?
11. How well does your care manager understand how your disability affects your needs and the importance of being responsive?

Health Related Social Needs

12. What transportation services do you need to access healthcare?
13. What difficulties have you experienced with accessing transportation services?
14. Can you describe any difficulties you have experienced in accessing and maintaining your mobility equipment (e.g. wheelchair)?
15. How does your physical disability affect where you choose to live or how you can function in your home?
16. How does having a physical disability affect social support and connection to your community?
17. What do you do when you have a problem with services? Is the process clear to you on how to file a complaint or an appeal?
18. Have you ever filed a grievance with your health insurance plan? If so, what was the outcome? Were you satisfied with the outcome?
19. Do you feel like your plan has providers who understand your disability and provide disability competent, accessible health care?

Primary and Preventive Care

We know that there are health risks associated with having a physical disability that can be prevented with proactive and timely care. The next questions ask about Primary and preventive care.

20. Can you describe any difficulties you've experienced with accessing diagnostic tests such as mammograms or colonoscopies?
21. In what ways (if any) has your provider given you information about preventing wounds or respiratory infection, urinary tract infections?
22. Can you describe experiences you've had with your providing addressing a condition such as a wound or urinary tract infection?
23. Can you tell me about a time that your doctor helped you to get the tests, services, prescriptions that you needed?

Quality Assurance
When answering the following questions think about the patient or consumer satisfaction surveys that you've been asked to complete.

24. Do you fill out the customer satisfaction surveys from your health care plan or health care system?
    a. Why or why not?
26. What questions do you think are missing from patient satisfaction surveys?
    a. Probes: questions about your life, your services, your disability
27. Other than patient satisfaction surveys, can you think of any other ways that plans could evaluate if patients with disabilities are receiving good care?

Provider Focus Group Guide

Intro: In this focus group, we hope to hear about your experiences as providers navigating care for people with physical disabilities. This includes navigating your experiences with accessing the services your patients need.

Does anyone have any questions before we get started?

1. How often do you see people with physical disabilities in your practice?
2. What percentage of your patients do you feel already have adequate access to the resources they need?
    a. For those that do have adequate resources why do you think that is?
3. What are the most critical referrals or services that your patients with physical disabilities need to maintain their health and live a full life? (have examples ready if needed)
    a. What resources, if any, do you use to access those referrals or services for your patients with physical disability?
4. Are there factors that affect your confidence that your patient will be able to access those referrals or services without facing barriers? (e.g. unaware of places I can refer to, place is likely to not be able to accommodate someone in a wheelchair)
5. How much does knowledge of services play a role?
    a. How about knowledge about insurance benefits?
    b. Can you give me an example?
6. How often do you experience barriers to referring a patient because the referral or resources who can accommodate your patient's needs are not available or because you are not sure about the best place or way to refer?
    a. Can you give me an example?
7. What is your experience working with social work, case management or other care coordination services?
8. Prior evidence indicates that while providers want to give the best care to their patients, they feel less confident to provide the same quality of care to people with disabilities as they do to people without disabilities. Based on your experience as a provider here in NY, what could be local factors or gaps which contribute to this?