Insights from Online Focus Groups with Medicaid Beneficiaries

Understanding the Value of the Medicaid Non-Emergency Medical Transportation (NEMT) Benefit

CONDUCTED FOR THE MEDICAID AND CHIP PAYMENT AND ACCESS COMMISSION (MACPAC) PREPARED BY PERRYUNDEM

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JUNE 2021



BACKGROUND

MACPAC commissioned eight online video focus groups with Medicaid beneficiaries (or a caregiver representative) who are enrolled in the non-emergency medical transportation (NEMT) benefit and have experience using these services.

- The eight online focus groups were conducted from September to November 2020 by PerryUndem with residents in six states: Arizona, Connecticut, Georgia, Indiana, Massachusetts, and Texas. These states were selected to align with MACPAC's larger study on NEMT.
- Each group lasted 90 minutes and included between four and seven participants.
- To make participating in this research as accessible as possible, some participants participated by phone while others participated by video from laptops or mobile phones.



BACKGROUND

State partners helped identify potential focus group participants.

- We held one focus group each with residents of Connecticut, Georgia, Indiana, and Massachusetts. Additionally, we held two focus groups with Arizona residents, one with Spanish-speaking residents from Texas and Arizona, and one group with residents from Texas and Massachusetts together.
- Our recruitment for this project was made possible because of the help of different partners across these states. These are partners that have relationships with Medicaid beneficiaries who use NEMT.
- The partners who helped with this included state Medicaid agencies, health plans, NEMT transportation providers, and local health service organizations.
- These partners worked with MACPAC and PerryUndem to identify and provide contact information for people who use NEMT.
 PerryUndem then reached out to potential participants to see if they were willing and available to join a focus group discussion.

FOCUS GROUP PARTICIPANTS

The research participants included in the focus groups have chronic conditions that require monthly to daily mental or physical health care visits.

- Focus group participants have (or are caring for someone who has): end-stage renal disease (ESRD), cancer, high blood pressure, back problems, hip and knee problems, neuropathy, cirrhosis of the liver, vision issues, asthma and other breathing issues, autoimmune disorders, heart disease, PTSD, bipolar, anxiety, depression, and substance use disorder (SUD). Some participants also use wheelchairs, including two participants with quadriplegia and paraplegia due to spinal injuries.
- Many of the participants have multiple conditions and complex needs, which makes things especially difficult for them to manage.
- The focus group participants have been using NEMT services anywhere from a few months to over 10 years.
- Most participants use NEMT at least weekly, and some use it daily. A few participants use NEMT infrequently.



- Focus group participants reflected a mix of different genders, age groups, geographic areas and races and ethnicities.
- 31 women and 10 men;
- 24 participants age 45 years or older and 17 participants age 44 years or younger;

We had 41 total participants in the focus groups across these 6 states. They included:

- 27 participants enrolled in Medicaid only, and 14 participants who were dually eligible for Medicare and Medicaid;
- 14 residents of urban areas, 7 residents of suburban areas, 14 residents of small towns, and 6 residents of rural areas;
- 14 white participants, 13 Black participants, 9 Latinx participants, 2 Asian American and Pacific Islander participants, 1 American Indian participant, 2 participants who identified as mixed race; and;
- 34 participants who use NEMT themselves, and 7 participants who are caregivers for people using NEMT, including several parents of children using NEMT.

- FOCUS GROUP PARTICIPANTS

RECRUITMENT

It is challenging to reach NEMT users and to include them in focus group research. We appreciate the assistance of the following organizations in helping us identify focus group participants:

Arizona:

- Arizona Health Care Cost Containment System
 Administration
- Arizona Complete Health
- United Health Care Community Plan Banner Health
- Care1st Health Plan Arizona

Indiana:

- MHS Indiana
- Indiana Medicaid
- CareSource
- MDWise

Texas:

- Children's Medical Center
- LogistiCare

Connecticut:

- Veyo
- Medical-Legal Partnership Center for Children's Advocacy

Georgia:

- Georgia Medicaid
- National Alliance on Mental Illness Georgia
- LogistiCare
- Southeastrans

Massachusetts:

- MassHealth
- Massachusetts Human Service
 Transportation Office

6



NEMT Context.

States are required to provide NEMT to and from medical appointments for Medicaid beneficiaries who have no other means of transportation. Additionally, states are required to provide assistance with transportation to children and their families as part of the early and periodic screening, diagnostic, and treatment services benefit.

- States are required to ensure necessary transportation and to use the most appropriate form of transportation for the beneficiary.
- The NEMT benefit varies by state but generally covers a broad range of transportation services including trips in taxis, buses, vans, personal vehicles belonging to the beneficiary and their family or friends, and increasingly, transportation network companies (TNCs) such as Uber and Lyft. Use of public transportation for NEMT purposes varies considerably across states and even within states as public transportation is not available in all areas.
- States may limit the number of trips that are permitted or require prior authorization for trips. Some states require certain beneficiaries to pay a nominal copayment to use NEMT services.



NEMT CONTEXT

States have discretion over which models they use to deliver NEMT and may use more than one approach to accommodate varying beneficiary needs, delivery systems, and geographic areas.

- Under a fee-for-service (FFS) model (also referred to as an in-house model), the state manages the benefit directly and pays for services on a FFS basis.
- States may contract with a third-party broker. Under this model, states contract with a transportation broker to manage the benefit and deliver services. Brokers may be paid on a capitated or FFS basis.
- States may also contract with managed care plans to manage the benefit and deliver NEMT services along with other Medicaid services.

Key Insights.

- 1. Nearly all participants expressed that NEMT is critical for managing their mental and physical health or the health of someone in their care.
- 2. Most participants reported that they use NEMT because they have frequent or serious needs for medical services and have no other means of reliable, affordable, or appropriate transportation. Without the transportation service, most participants said they would have no other way to get to their medical appointments. Many reported that they often missed appointments or failed to schedule them at all before they began using NEMT.
- 3. Almost all participants said their physical health would deteriorate without access to NEMT. Some called the transportation services the difference between "life or death." In fact, one participant who missed dialysis appointments because she lacked transportation during the COVID-19 pandemic was hospitalized as a result.
- 4. Several participants with disabilities or physical limitations emphasized the sense of independence NEMT provides them, as they would otherwise have limited ability to leave the house. They noted that this independence is important for their emotional health.

- 5. Participants reported that NEMT lessens their need to rely on friends and family for rides, in addition to helping them maintain and improve their physical and emotional health.
- 6. Most participants said they had experienced considerable challenges related to timeliness and reliability of pickups; specifically, drivers arrived too early, too late, or not at all. These issues resulted in participants missing important medical appointments or being left in unsafe situations. Participants did not uniformly point to the same root causes for these challenges: while some blamed drivers, others blamed the dispatching service or broker.
- 7. Nearly all participants noted examples of customer service deficiencies, including rude or unprofessional drivers or call center representatives.
- 8. Most participants felt there is little recourse for them when challenges arise. For example, many had, at some point, submitted a complaint without a satisfactory solution. They generally felt that there is a lack of accountability for brokers and drivers.

- 9. Participants felt that some NEMT policies are not practical or fair. Examples include policies that require beneficiaries to share rides or use public transportation even when doing so is not practical; policies that require beneficiaries to schedule rides three days in advance; policies that require riders to be ready within five minutes of a ride's arrival, even when it is early; and policies that preclude parents from bringing their children along in rides.
- 10. There is wide variation in beneficiary experiences across different states and entities providing NEMT. For example, one beneficiary described the difference between two different transportation providers as "night and day."
- 11. Reflecting on their experiences, participants suggested ways to improve NEMT; for example, taking steps to improve dispatching processes and prevent overcrowding and excessive wait times, and implementing stronger background checks for drivers.

- 12. Participants felt they would benefit from more flexibility for certain NEMT rules, including the flexibility to use NEMT for non-medical purposes, such as trips to the grocery store. They also would like more flexibility around some of the policies mentioned on the previous slide (e.g., parents being able to bring children).
- 13. Only a small number of focus group participants had used Lyft or another TNC for NEMT. Some also specifically mentioned wanting to be able to use Lyft and Uber for NEMT services because the drivers are accountable for their ratings, are timely, and have better-maintained vehicles.
- 14. The participants generally liked the idea of introducing new technologies into NEMT, such as an app to help schedule appointments and track their rides. However, some participants felt it would be too difficult to use, especially for people without data plans or reliable cellular service, and for people with certain disabilities or limitations.



MEDICAID COVERAGE

The participants were universally happy with their Medicaid coverage (or combination with Medicare).

- Participants said that Medicaid gives them access to the medical care they need and would otherwise not be able to access.
- Participants used the words "beautiful," "perfect,"
 "blessed," "wonderful," and "responsive" to describe the Medicaid program.
- Some participants voiced concern that they would lose their Medicaid benefits if they found employment or worked full time.



MEDICAID COVERAGE

We are also very grateful because she's been to the hospital, I don't know how many times, 50 times . . . If we didn't have Medicaid, we couldn't pay for all those hospitalizations. (Arizona woman, Spanish-speaking group, caretaker)

I don't have copays when I pick up my prescriptions or when I go see my doctors or when I go get labs done. Which means I don't have to like think about am I going to spend this money on food or transportation or medicine. Like these are things that I would otherwise really think about. (Massachusetts woman) You couldn't actually buy health care this good . . . We're very blessed to live in a state where we're covered and where we actually get transportation. A lot of people in other parts of the country aren't as lucky as we are, so I feel very blessed. (Massachusetts woman)

I have to tell you, if it wasn't for Medicaid my daughter wouldn't be here. And if they were to come and tell me that she is no longer eligible, I would have to completely stop working. I mean there's just no way. Like I haven't had a problem and she has like really expensive medication. I mean it's a blessing. (Texas woman, caregiver) I personally love it. . . I think I've always been able to get like my services, like it's kind of worry free . . . When I think about getting a job, I even stress out about it because I'm like, I'm going to lose my insurance, so yeah. (Arizona woman)

You know, if I didn't have Medicaid, you know, like when I used to work, I had Blue Cross/Blue Shield, it was hard yeah and it cost a lot. (Massachusetts man)

I'm pretty happy with the care that I get. I can't complain. I won't lie. I think I have some of the best doctors in the state. (Indiana man)

COVID-19 IMPACTS

Participants reported being significantly affected, emotionally, financially, and physically by the COVID-19 pandemic. Many felt especially vulnerable because of their underlying health conditions.

- Participants reported increased stress, anxiety, and depression and feelings of isolation or boredom following COVID-19 and associated lockdowns.
- Many participants feared contracting COVID-19 because of their pre-existing conditions – they felt vulnerable. Some participants did contract COVID-19, or lost friends or family members to the virus.
- Several participants reported being affected financially, including being laid off or having reduced hours (themselves or other family members).

- COVID-19 IMPACTS

I'm losing my house. I've lost the electric in my house. I've just about lost everything at this point. . . My health is left—the only thing that's left and it's not very good . . . We're waiting on disability for both of us. We tried to get the kids to help, but then they got laid off and quarantined and everything from their jobs . . . there was just nothing, no way to do anything. (Indiana woman)

I mean I thank God that I'm alive, and I haven't been affected as of yet. But every day is a challenge—especially going out, you know, and taking public transportation and people not adhering to what they need to do for the safety of themselves and others. So that's where I am right now. (Connecticut man)

In July, me and my grandfather were diagnosed. Unfortunately, he didn't make it, and he passed away. . . So just dealing now with the aftermath of COVID, being personally affected by COVID, and then just trying to keep balanced and focused through it all by keeping myself busy. (Arizona woman)

And being in a wheelchair, and then being stuck inside, and then being vulnerable enough, you know, with, you know, being handicapped, I wasn't wanting to go around people at all of course. So I pretty much stayed in the apartment and that was really hard. (Georgia woman)

I have a genetic disorder, so part of it affects my immune system, it's suppressed. And so, basically, I have been in my house since March. I only leave to go to Boston to the hospital if I absolutely have to. . . I think just the isolation and also the thought of, like, if I'm around the wrong person I might die was just looming over me, was really like hard. (Massachusetts woman)

— DISRUPTIONS IN CARE FOLLOWING COVID-19

The pandemic caused disruptions in care for many participants.

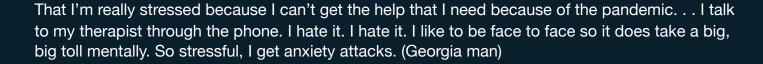
- Participants reported a variety of different reasons for disruptions in care, including medical facility shutdowns, cancellation of services such as adult day health, and fewer available appointments.
- Some participants reported difficulty securing transportation to appointments, which they attributed to fewer drivers willing to make trips. A small number of participants had contracted but recovered from COVID-19 and expressed concern that their trip requests were still being denied by drivers despite having recovered.
- Many participants, particularly those with underlying health conditions, reported fear of going to the doctor. For example, all participants in the Georgia focus group said they were avoiding medical visits and had postponed preventive care.
- Although telehealth became increasingly available to help address disruptions in care, most participants did not like using telehealth compared to an in-person visit. Some participants reported that they did not have reliable access to telehealth or sufficient internet bandwidth to use telehealth.



— DISRUPTIONS IN CARE FOLLLOWING COVID-19

It has changed. I have missed I'll say probably like five dialysis appointments this like past two months. I've missed a couple because there was no transportation and there was no way for me to get to my appointment. . . I actually just got out of the hospital because I had fluid overload and I missed my appointment. (Georgia woman)

I'm in a similar I guess if you want to call it the rheumatoid club as the last lady that was speaking. And since COVID it's been a nightmare getting any treatment because they don't want to see you in person to give you injections for pain. (Arizona woman)



I was going to (a spinal center) three days a week for two hours each day. And then when COVID came . . . they closed their doors and wouldn't let anybody outside in. So, in fact, that's hurt me as far as the strength in my muscles and my workouts, and everything that I did and I loved, you know, taken it away, you know, for so many months. (Georgia woman)

Right before COVID I was going daily to the doctors, different doctors for different things. And now it might be once a month. (Indiana woman)



Reasons for using NEMT.

— NEMT'S IMPORTANCE

Participants reported a variety of different barriers to transportation.

- Many participants did not have a car or a driver's license.
- Some participants were unable to drive or use public transportation because of their medical conditions, including having impaired vision, being immunocompromised, a weakened immune system, or other mobility issues.
- A few participants required a specialty vehicle such as a wheelchair van.
- Many participants could not afford the cost of transportation. This was a particular issue for those living in rural areas who often traveled an hour or more for their medical care, and for those in need of frequent transportation to reoccurring appointments (e.g., dialysis, day health services, substance use disorder (SUD) treatment, physical therapy).
- Public transportation was not available or took too long for some. This issue was more frequently experienced by, but not limited to, beneficiaries living in rural areas.
- Participants did not have, or could not rely on, friends or family to drive them to appointments, or they felt the burden was too great on their loved ones who would have to miss work, school, or arrange childcare to do so.

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— NEMT'S IMPORTANCE

Participants talked about the reasons they signed up for NEMT.

- Many participants signed up because they developed a condition that requires frequent medical appointments. For example, those with ESRD must frequently attend dialysis appointments. Some with SUD are in need of regular treatment including medication for opioid use disorder (MOUD).
- Some participants had experienced a major injury resulting in physical limitations or disability and require frequent specialty care and physical therapy.
- Some participants signed up for NEMT because they need to travel long distances to see a specific doctor or specialist. For example, one mother of a child with a heart condition living in a rural area of Texas needed mileage reimbursement and coverage for overnight trips.
- Several other participants with behavioral or physical health limitations were set up with NEMT to help them attend day health or other habilitative services.

— NEMT'S IMPORTANCE

(My daughter) needs to see a developmental specialist in Phoenix and that's something we will have to call medical transport for because I can't afford to drive all the way to Phoenix . . . That's a three-hour drive, and right now with me not working, that's an expensive drive. (Arizona woman, caretaker)

I'm in a small, you know suburb town and there is no transportation. And a lot of times I have to travel out of town because the doctors, especially specialists in my area, they don't take Medicaid, so a lot of us have to travel farther. (Connecticut woman)

I have to depend on the services because I am in a 375-pound wheelchair. I have no other means of doing it . . . It's my livelihood . . . If I can't go to physical therapy, then I can't get any better in my life. . . . Being a quad you have to keep exercising. It's your mental health. If you're just sitting here wasting away, then what good is it, you know. (Georgia woman)

I live off of disability, it ain't much . . . To pay \$100, \$125 each way, you know to get to an appointment once a week, and that's not feasible you know. I would be missing a lot of appointments. I can't afford all that. We don't have a bus thing that runs here normally. It's not like a major city . . . where you can get a bus every two minutes . . . Over here you get a bus every four, six hours I think they run. I would definitely be really hurt if I ain't have that (transportation). (Massachusetts man)

Well, I didn't have a vehicle when I moved to Indiana. Right after I moved here from New York I got sick. And so I wasn't working so I didn't have the, no paycheck stubs with income to go apply for a vehicle. (Indiana woman)

NEMT USAGE

The frequency with which participants used NEMT, and the types of services they used NEMT to access, varied based on their condition, individual characteristics, and NEMT rules.

- Participants who reported using NEMT most frequently included those receiving dialysis treatment, physical therapy, behavioral health services, day health services, and SUD treatment (such as methadone maintenance).
- Among participants who reported using NEMT episodically, some have serious health conditions requiring relatively infrequent medical appointments. Others do not have serious health conditions but used the service for routine primary care and specialty services (e.g., for annual well visits, podiatry appointments, to participate in sleep studies).
- Most participants were only permitted to use NEMT to go to medical appointments or pick up prescriptions. However, some participants had run into administrative difficulties in trying to do both in the same trip. For example, a couple of participants said drivers told them they couldn't change from the agreed upon ride or route.



NEMT USES

Examples of how participants used transportation services.

- A Georgia woman with quadriplegia used NEMT to go to a spinal care center three days a week. She cited this therapy as critical to maintaining her strength and mental health.
- An Arizona man who was left with a broken femur and hip, among other injuries following a car accident, used NEMT for physical and occupational therapy to help his mobility recover.
- An Indiana woman who has cirrhosis of the liver, neuropathy, and degenerative discs causing reduced walking ability, used NEMT to go to physical therapy two to three times a week and other specialists a few times a year.
- A Massachusetts woman with ESRD signed up for NEMT when she broke her hip and could no longer drive herself to dialysis.
- A Massachusetts man with SUD used NEMT to go to a methadone clinic seven days a week to assist his ongoing recovery from addiction.
- An Arizona mother of a child with autism used NEMT regularly to take her daughter to see developmental specialists. Her daughter also participates in a respite and living skills program that arranges transportation funded by Medicaid.

Experiences using NEMT.

APPROVAL FOR NEMT SERVICES

The process for gaining initial approval to use NEMT varied by state, but was not difficult to navigate for most participants.

- Most focus group participants learned about NEMT services from case or social workers, health care providers such as nurses and therapists, and other patients they met at their treatments. Some also found out about the service through friends and family. A small number found out through their health plan or the state Medicaid program.
- Many participants received help signing up for NEMT from a case worker, social worker, counselor, or health care provider. This was most often the case for those receiving dialysis.
- The request and approval process for NEMT services differs by state. But, most participants said the process worked reasonably well. For example, in Massachusetts, participants were able to work with health care providers to submit the state authorization form without issue.

— NEMT SCHEDULING PROCESS

The process for scheduling NEMT varied depending on the entity responsible for delivering benefits (i.e., state, managed care plan, broker). It may also have varied based on the type of transportation being requested and the person or entity arranging transportation.

- Most participants said they scheduled their own rides. Others
 received help from a family member. Those who reported that they
 schedule their rides tended to be younger, living on their own, or in
 slightly better health than those who have other people help
 schedule for them.
- Participants who said they use NEMT multiple times per week (e.g., people undergoing dialysis or SUD treatment) generally had "blanket" approvals or standing reservations scheduled months in advance. This meant that beneficiaries or caregivers did not need to individually schedule or get approval for each ride.
- Participants scheduled rides in different ways, usually depending on the state's process. Some called brokers, others talked to their managed care plan, and a few contacted the state office directly. A couple of participants said they used a web portal to schedule appointments.
- Participants without standing appointments reserved transportation on an ad-hoc basis.

— NEMT SCHEDULING PROCESS

The assigned mode of transportation varied depending on state and provider.

- The most common modes of transportation used by participants were shared or individual cars (including taxis) or vans. A small number had used TNCs or public transportation.
- Most participants preferred to ride individually to appointments, but many were regularly assigned to shared vans. Participants seemed to think that shared vans were used more often in rural areas with limited options, or if participants needed specific things such as wheelchair access. However, some participants said they have had shared rides less often (or not at all) during COVID-19.
- Some participants experienced challenges associated with shared rides, which we discuss later on (slide 36).
- Some participants noted that the assigned type of transportation was not always appropriate. For example, a Connecticut woman complained that her NEMT provider wanted her to use a commuter bus to go to appointments, which was impractical because of the commuter bus schedule.



Challenges using NEMT.

NEMT CHALLENGES: TIMELINESS AND READINESS

The most common NEMT challenges were related to reliability and timeliness of pick-ups. Sometimes these issues made participants feel like NEMT could not be relied on for transportation.

- Drivers arriving too early. Several participants described drivers arriving an hour or more before the scheduled time. As a result, the participants 1) were not ready, 2) were not waiting outside and the driver left, or 3) had to wait a long time in the medical office until their actual appointment time.
- Drivers arriving too late. Several participants reported missing appointments as a result of drivers showing up past the scheduled time. One Indiana woman said she had missed multiple dialysis appointments because drivers came too late. Additionally, some participants reported waiting as long as three hours to be picked up for their return trip.
- Drivers not showing up at all or cancelling with little notice. Though less common than late pick-ups or drop-offs, driver no-shows or late cancellations also led some participants to miss appointments. One Arizona man talked about missing more than 10 appointments over the last year because drivers didn't show up.
- Drivers not arriving for return trips. Some participants talked about being stranded when drivers did not come to pick them up from appointments. One participant from Connecticut described her elderly, disabled father being left at a doctor's appointment.

— NEMT CHALLENGES: TIMELINESS AND READINESS

It's already five, and now that it is cold, there is nobody, and you call and you call the office, and we sent him already, just wait, and they don't come. To the point where I've had to call someone from the family . . . Once, they completely left me there, and they kept saying it's coming, it's coming, and it never came. (Arizona woman, Spanish-speaking group)

I had to make alternatives because I can't trust them, because every time I scheduled the ride they never showed up, therefore it kept bumping my appointments back. If I were to miss one more they would not have done the study. That's the thing; you miss so many appointments those physicians will not see you. (Connecticut woman)

I can't stand in the parking lot for an hour. I physically can't do that, and I shouldn't have to. (Massachusetts woman)

I mean nothing is on time. Like I don't think I'm ever on time. I mean I have missed so many dialysis treatments because of a driver either not showing up at all or being at the wrong location or coming at the completely wrong time. (Indiana woman)

My appointment ain't until one o'clock. I waited all the way to 12:45 when the person came, and now he is drag racing all the way there to my doctor's appointment. I called (the doctor), I said . . . I'm going to be about 30 minutes late or 15 minutes, okay we'll take that. But if you don't get here by 1:20, your appointment is canceled. I done got all the way there and get registered and everything and then they canceled it. (Arizona man)



NEMT CHALLENGES: SCHEDULING

Participants reported experiencing a variety of difficulties in scheduling and confirming transportation.

- Some participants experienced delays in getting approval or mileage reimbursement for trips, resulting in frustration and financial strain.
- Some participants experienced difficulty providing the information required to book rides and expressed desire for a simpler process. For example, some participants explained that they didn't always have their insurance or specific provider information readily available.
- A participant from Connecticut talked about how rides are not actually guaranteed even when scheduled. She was told by the statewide broker that rides depend on driver availability. This means beneficiaries might find out the day of their appointments that no driver is available.
- Some participants complained of long hold times, or no one picking up the phone when they called to reserve trips.

NEMT CHALLENGES: SHARED RIDES

Shared rides created a number of difficulties, especially for people in rural areas.

- A number of participants talked about having to travel far out of their way to pick up other riders, adding hours onto trip times. For example, a participant from Indiana shared that she once had to travel an extra 100 miles to pick up another rider, resulting in an unnecessarily long round trip: she was picked up at 10:45 AM and dropped off at 6:30 PM.
- Some participants described physical discomfort of riding in a crowded car full of riders. For example, one Massachusetts woman talked about having to ride in the back of a sedan with three larger men, which made the ride cramped and uncomfortable for her.
- Participants with physical limitations also found shared vans difficult to manage, especially if they had to climb into back seats or past other riders.



Some participants believed challenges are attributable to brokers and dispatchers, rather than drivers or NEMT providers.

- Participants highlighted different customer service issues, including long hold times, dropped calls and rude or unprofessional behavior on the part of dispatchers and customer service agents.
- Some participants complained of brokers overbooking appointments, which resulted in driver no-shows or last-minute cancellations.
- Some participants said brokers failed to assign a driver to a scheduled ride. In some cases, this was because systems allow drivers to accept or refuse rides they view as undesirable (e.g., too short or too long).
- Participants felt dispatchers do not always communicate effectively with the drivers about the schedule, when they would need to arrive, or what specific needs a participant might have.
- Some participants cited a lack of training and empathy among dispatchers and brokers. For participants, this meant that dispatchers weren't really grasping the difficulties of being without transportation or having physical limitations.



— NEMT CHALLENGES: DRIVERS

While a number of participants felt that most NEMT drivers are "great," others expressed concerns about reckless or unprofessional behavior on the part of drivers.

- Participants described examples of dangerous driver behavior including drivers who talked on their phones or texted while driving, had conversations that made participants feel unsafe, sped or drove unsafely, or did not wear masks.
- Participants also described examples of unprofessional driver behavior including
 - drivers not protecting rider confidentiality;
 - drivers refusing to accommodate special needs of participants even if those needs were specified ahead of time (such as to accommodate a rider who needed to sit in the front seat due to a physical limitation);
 - language barriers between the riders and drivers; and
 - drivers who made personal stops or pick up their own friends or family while completing an NEMT ride.

— NEMT CHALLENGES: DRIVERS

They're okay, but I mean it's just unprofessional. They always have the music on too loud. They're constantly on their phones, constantly, like almost like the whole time I ride up to Indianapolis the guy was on his phone. That's not safe for one thing, and they just they discuss you know things they shouldn't, unprofessional, you know, sitting there talking. They're talking about political stuff and then saying that they don't really think we should be wearing masks. And I said well you need to keep yours on, you know, because I always wear a mask. (Indiana woman)



Yeah, they (drivers) complain all the time. They don't like their job. . . They don't like to drive to this area of town, or they don't like to drive to this part of Tucson, or they don't like to drive to Benson, everything you can think of. They're upset that they have to do this, and they're just complaining. It makes you feel awful that they are just so unhappy that they have to drive you. (Arizona woman)

I actually was making a prayer because I thought the guy was going to get in an accident how crazy he was driving. . . He came late and he's driving like crazy down the highway. I'm still in a (wheel) chair; I'm like wait a minute I don't want to get in another accident. (Georgia man)

I had to go into Boston, and the fellow that drove me didn't speak any English. He sped, he tailgated, he wouldn't listen to me. I got out of the car shaking. (Massachusetts woman)

It is a very scary situation. You don't have to do a hundred miles an hour to get from East Phoenix to West Phoenix. You don't have to do that. But they be driving over the speed limit law. (Arizona woman)

NEMT CHALLENGES: CONFLICT RESOLUTION

Participants generally felt that drivers and brokers lack accountability. Many felt they have little recourse when issues arise.

- Several participants had submitted complaints about drivers, late pick ups, or other issues, but were never offered a resolution and never heard back.
- One participant said that making a complaint would make no difference because, in her rural area of Indiana, there are just two NEMT providers and no option to use a Lyft or Uber.
- One participant, residing in a rural area, expressed fear that if she complained, she would end up with a "reputation" among the small number of drivers in her area and would lose her access to transportation services.

- Even some participants residing in more populous areas feel that because there are few choices in transportation service companies, complaining wouldn't make a difference.
- Participants in some states were subject to rules requiring them to submit a specific number of complaints about a driver or NEMT provider before they would be assigned to a different one. Some participants highlighted this as an unfair policy because it resulted in people having to ride with drivers, or in vehicles, that made them uncomfortable.
- Despite these challenges, some participants who filed complaints did get a satisfactory solution. For example, a man in Indiana who was unhappy made complaints to his Medicaid provider and was able to change his transportation services and driver.



— NEMT CHALLENGES: CONFLICT RESOLUTION

It's just crazy. Like you have to get evidence for these things, you have to get three complaints and switch the company, which is so ridiculous because I've had sexual harassment too, and I had to wait for three times for something to happen to change the company so I wouldn't get that driver. (Massachusetts woman)

I had some problems with a specific transportation company over and over again and I called my Medicaid provider and they said, would you like to put this on a formal complaint? And I said yes I did, and I put it on a formal complaint and then I was put on a do not ride order with that company. Do not transport and I got a completely different transportation company with a completely different driver, completely different boss and I haven't had an issue since. (Indiana man)

I've never actually got a good resolution for a problem. They say you need to have three complaints against the specific company before they will do anything. (Massachusetts man)

[My driver] said, no, there was nothing on his screen that I needed something special. I said, no, it is written with the insurance that I need to sit in the front seat...he was arguing, and he slammed the door and all that. And my daughter came, and she said, why are you behaving like that? And he started to yell at us, and my daughter said, get out, you don't have to put up with it, and we came down, and who knows what he said in his language, and he slammed the doors when he closed them, and he left really fast. (Texas woman)

— NEMT CHALLENGES: DIFFERENCES ACROSS STATES/PROVIDERS

There appears to be wide variation in beneficiary experiences across different states and entities providing NEMT.

- Some participants had recently moved to a new state and were struck by the different rules and processes for NEMT in their new state. For example, one participant who had moved from Arizona to Indiana noted that in Arizona, she was able to use Lyft or taxis for NEMT and that the transportation services were reliable and comfortable.
 However, since moving to a rural area of Indiana, she has had to rely on van services that are unreliable.
- Participants described vast differences in quality between different transportation companies. For example, one participant had previously been assigned to a consistently reliable provider, but was transferred to a new provider. His new provider had missed multiple appointments in the first month, causing concern about his ability to keep up with his SUD treatment.
- Participants in Connecticut felt that the state's recent move to a new statewide broker had resulted in a reduction in reliability and quality of service.

— NEMT CHALLENGES: RULES

The rules around scheduling and ride protocols created challenges for many participants.

- Participants from several different states discussed rules requiring them to book rides two to three days in advance. These rules were challenging in certain situations; for example, when beneficiaries were told to come into the doctor right away, an appointment was changed, they got off a waitlist, or they were leaving the hospital.
- For parents, rules about not being able to bring children along for rides were problematic. Some talked about having to plead with drivers on a case-by-case basis to make exceptions, others said the policy makes it impossible to go to certain appointments if they don't have childcare (especially during COVID-19).
- Participants also felt that certain policies were too harsh; for example, rules that required them to be outside within five minutes of the driver's arrival (or drivers may leave) even if the driver arrives early. A couple of participants cited physical limitations that make it more difficult for them to get from their apartments to the street within five minutes.



— NEMT CHALLENGES: RULES



When I have been in the hospital for a very long time, and I have no way to get back, I have requested transportation, and no, you didn't call us in advance. First of all, when a person is going to leave the hospital, it is like an estimate, we don't know exactly when the doctor will say you can go home . . . So, how am I going to coordinate that? (Arizona woman, Spanish-speaking group).

We've had to cancel this last (medical appointment) because . . . like a doctor will say, like in an emergency situation, you need to get in here before we prescribe the medicine back to you again. And they (transportation service) want a two-day notice. There is no and ifs or buts, no way around that, you've got to give them a two-day notice. (Indiana woman)

When your appointment gets changed . . . and you call for a ride . . . some (allow an override of the three-day notice requirement) as a onetime courtesy, but then they would have to call your doctor's office and verify the appointment. And sometimes it's hard to get that appointment verified because the phones are busy or they just can't get through with the behavioral health company that I work with for methadone, so that has been my only issue. (Arizona woman)

Suggested improvements to NEMT.

NEMT IMPROVEMENTS

Participants volunteered ideas for improvements related to reliability, scheduling, training, and vetting of drivers.

- Participants value reliability and on-time performance. Improved reliability was the most commonly cited desired improvement.
- Participants want a less complicated scheduling process that allows them to schedule rides quickly online or over the phone.
- Participants feel NEMT programs would benefit from better screening processes for drivers, including stricter background checks.
- They called for more "courteous" dispatchers and drivers. They talked about the need for greater respect. They also called for additional training of dispatchers and drivers in working with people with different disabilities, including sensitivity training. Several participants emphasized that just because they're poor or disabled doesn't mean they should be disrespected.



NEMT IMPROVEMENTS

Participants also talked about other possible improvements to rules and processes.

- Several participants said they wish they had known about NEMT services earlier. For this reason, they suggested that NEMT be more widely promoted as an available service.
- Participants want more flexibility in making reservations, including the ability to make same-day reservations or more exceptions to the 72-hour advance policy.
- Participants would like to be able to use the service for more than just medical appointments (e.g., rides to the grocery store). A small number of participants are currently able to do so because of additional flexibility granted by their health plans.

— NEMT IMPROVEMENTS

Generally, participants had positive things to say about their experiences with Uber or Lyft, and wanted to be able to use them more often for NEMT.

- Most participants have not used Uber or Lyft yet for NEMT. Most rural participants do not think these will ever be an option.
- Several participants who have used Uber or Lyft said that Uber and Lyft drivers are more professional and reliable than drivers from other transportation companies, and that their vehicles are cleaner and newer than other companies' vehicles. They also feel they are easier to track and more accountable.
- Some participants would like to receive a voucher or code to use a cab, Uber, or Lyft without having to go through the normal NEMT request and scheduling processes.
- In many states, Ubers and Lyfts are only sent as a back-up option, when the originally scheduled ride does not show up. Several participants want them to be a first option.

— NEMT IMPROVEMENTS

Some participants liked the idea of introducing new technologies into NEMT, such as an app to schedule and manage their rides and track drivers. Others felt that such technologies could add confusion or be too difficult to use.

- Most participants feel an app would be helpful something like they already use for Uber and Lyft. They particularly like being able to track the location of their driver. One Indiana woman talked about how nice it would be to track the driver to avoid waiting too long in the sun.
- Some participants would like an app, or other technology, that allows them to directly communicate with the driver and avoid the dispatcher or call center.
- A few participants said it would make them more comfortable to know there is a record of their location and their communications with the driver.
- Several participants were hesitant about using apps or other new technologies. For example, one participant worried an app may not be easy for for someone with cognitive difficulties to use. Another mentioned that an app would not be valuable if you did not have a data plan. One caregiver said that the system was already complicated enough, and that her father would be unable to use mobile apps.

NEMT's importance.

NEMT'S IMPORTANCE FOR PHYSICAL HEALTH

NEMT is important for their physical health and managing chronic conditions.

- Many participants, particularly those with serious chronic conditions like ESRD, feel that continued access and regular access to treatments and medical services is saving their lives.
- Many participants felt that NEMT is key to allowing them to access regular services, because of the barriers they face to regular transportation.
- Participants expressed worry about continuing to access care without NEMT.



— NEMT'S IMPORTANCE FOR PHYSICAL HEALTH



[These services are] pretty much life or death for me. Because if she doesn't get to dialysis to get her blood cleaned or filtered every so many days, she could die. (Texas woman, caretaker)

I think the provision of transportation for medical services and our medical services is a huge sign of respect for like the humanity in all of us, and how much we all deserve to access high quality care. (Massachusetts woman)

For me it's really important. I really value the transportation services. . . If I didn't have them, I don't know what to do because . . . I live in a small town, and we don't have a really good city transportation system, so it's like impossible. So, the fact that we have this for health care makes it really easy. (Arizona woman)

Sometimes the pain is overwhelming, but . . . just having support and being able to just get to my appointments, that's been the main thing. As long as I can stay consistent in getting . . . access to my appointments to get my meds, then I found that I've been balanced, I've been stable, and everything. I've been able to maintain. (Georgia woman)

For me, without services it was very difficult because I'm in a very heavy chair and that is, I'm unable to transport this chair with an SUV. I have on occasion rented a trailer and I went out and bought a device called a chariot lift to place the power chair on. However, it's a difficult device to operate; it operates hydraulically. (Georgia man)

NEMT'S IMPORTANCE FOR EMOTIONAL HEALTH

NEMT helps beneficiaries maintain their emotional health, in addition to their physical health.

- Some participants highlighted the importance of NEMT in helping them access regular mental health or SUD services, which are vital to their productivity or recovery.
- NEMT rides made getting to and from appointments more manageable for participants with mental health challenges. For example, one participant shared that when she experiences heightened depression and anxiety, just leaving her home and getting on public transportation can be too much, and NEMT rides are a better solution.
- NEMT is helping several participants maintain their emotional health. Specifically, some participants talked about the emotional toll of being confined to their homes, and said that NEMT enables them to travel to day health programs, physical and occupational therapy, and other appointments that provide opportunities for human interaction and enrich their lives.

— NEMT'S IMPORTANCE FOR EMOTIONAL HEALTH



The transportation has like basically made my life possible, especially when I was more depressed and anxious, I like could barely leave the house. That was really the only way that I was making it to my doctor's appointments . . . I mean literally I was a shut-in, and I don't know how I could have functioned without (NEMT). (Massachusetts woman)

If it were to stop, I think it would be emotionally, just when you kind of asking that, it made me tense up. Because then it would kind of alter everything that I've gotten accustomed to. I think it would actually make me regress in my health, definitely my mental health, I know that it would. Financially, I wouldn't be able to handle trying to, you know, facilitate getting me a ride. I definitely can't do the bus. . . So I mean there is definitely no other way but for me to be able to have transportation. It would be life altering if I didn't have it. (Georgia woman)

— NEMT'S IMPORTANCE FOR INDEPENDENCE

NEMT also helps give more independence for participants, lessening their reliance on family members.

- Several participants reported that NEMT helped give them a sense of independence and being able to control their own lives, without having to rely on friends or family members to provide transportation.
- For some, particularly those with mobility challenges, they appreciated NEMT simply because it enabled them to "get out of the house" and continue with some normalcy to their lives.
- Many participants said having NEMT is greatly beneficial to their families. One participant said that without NEMT her mother would have to quit her fulltime job in order to transport her to and from her dialysis appointments.
- Some participants said that because of their mental and physical health challenges, trying to coordinate rides from family members and friends, or navigate public transportation or Uber and Lyft is too much for them to handle.



— NEMT'S IMPORTANCE ON INDEPENDENCE



I like the fact that it gets me out of the house to be able to socialize with other people, so that is a plus also. I'm not alone. (Georgia woman)

I like having the independence, so I don't have to rely on anybody or be afraid that my appointment is going to go too long and . . . put people out, so it is good to have the service. (Indiana woman)

Being alone, I don't have family out here you know. It's not easy, it won't be easy. (Massachusetts man)

It was also just having to you know be a burden to my kids. I'm the parent and it just made me feel as if I was insufficient or not enough because I was depending more on, you know, my daughter. And she was in college and I just, it was just horrible. So, you know the transportation has really been a God send. (Georgia woman)

I had to take rides from family before and it was very difficult because my mother, she works full time, she was a single parent. My father wasn't in the picture; the rest of my family had addictions and other issues and weren't really capable of being there. So, getting around was a struggle, and I hated having to be dependent on other people. So, yeah, it was frustrating all the way around before medical transport became a thing. (Connecticut man)

— LIFE WITHOUT NEMT

Participants expressed fear of the effects of losing NEMT.

- Many participants became anxious when we asked what would happen if they could not longer receive NEMT services. They had an emotional response to the question.
- The biggest fear among participants was that they would regress, and their health would deteriorate.
- Other participants said there would be mental health consequences. The peace of mind NEMT services provided, the sense of independence, and the ability just to leave their house would be lost.
- Many participants said there would be intense financial consequences of losing NEMT services, because they cannot afford to pay for services on their own, buy a car, or afford public transportation on a regular basis. This was particularly a concern for those living in rural areas.



— LIFE WITHOUT NEMT

For me, if the transportation services would stop, I mean I won't have transportation to go anywhere. I would be stuck at home and miss my appointments. (Georgia woman)

I mean as bad as [contractor] is, if we lose medical transport that will be catastrophic on a level, not just not for me, but for a lot of other people I know who either depend on it, or for that matter are considering using it. (Connecticut man)

It would be a struggle. I wouldn't be doing half of my health issues. . . I think my health would go downhill instead of you know, improving being uphill. . . And it would be disaster if we lose this. . . And for me it could mean life or death. I have a stint. I have a lot of breathing issues. There's a lot going on with me, so it could be detrimental to either life or death with me. (Connecticut woman)

Like there is no way because my mom still works you know full time, and our car isn't really up to going back and forth for the amount of time that we need to for all of my appointments to keep up with my health. So yeah, I'd have to cut back. (Massachusetts woman)



— FINAL THOUGHTS ON NEMT

It's a vital service especially to the disabled community. There obviously could be some oversight, but you know without it, I think that there are a lot of people that would not be able to access the health care they need. (Massachusetts woman)

The service is very much appreciated especially for somebody like me who has back and knee problems. You know I'm low income, I work part time, I'm very glad that the service is around. However, I do think there are some changes that could be made to it that could definitely improve upon their approach to it. Just maybe some general guidelines that these companies need to follow. (Massachusetts woman)

I think I would like more people to know that it's available. I've grown up in Massachusetts my whole life, and I can't believe that I was in my 30s before I knew that this was available. And I don't know if that's because I'm part of a minority group because my parents didn't speak English as a primary language. (Massachusetts woman)

It has been very useful, in spite of everything, I am happy having this transportation. If it weren't there, I don't know what I would do because my daughter works, the one I am with, the other one doesn't have a car. My son lives far. So, and they all have jobs, and I am not used to using the bus. I don't know how to use the bus. (Arizona woman, Spanish-speaking group)

Sometimes I think they don't really want you to know all the benefits, honestly. But when I do use it, it's very, very convenient. (Massachusetts woman)



PERRY UNDEM