

The Kentucky Department of Medicaid Services (DMS) through its contract, asked Navigant Consulting Inc. (Navigant) to review and find ways to make Kentucky's 1915(c) waivers better. A complete review needs to include the people most affected by the waivers so the team of Kentucky Medicaid staff and Navigant staff held focus groups across Kentucky. The focus groups included:

- People on waivers
- Caregivers
- Direct support professionals, such as case managers and home care aides
- Providers

In the focus groups, we talked about the current home and community based services (HCBS) waivers to get a better idea of what being on a waiver is like. We learned about what is working well and what could be made better. Four focus groups were held in 10 counties across the Commonwealth. The team talked to almost 500 people in a total of 40 focus groups. In this report, we present the comments that we heard most often in the focus groups.

DMS will look to these comments when making decisions about waiver programs. This report and the associated focus groups help DMS to have open and honest communication with people affected by the waivers throughout the program review process.

Top Focus Group Comments:

We heard many comments from the people in the focus groups. Some were about the strengths of today's programs that they wish to see in the future. We list a few below:

- Many people on the waivers talked about how the waivers make their lives better. They said the waivers let people live on their own and stay in their homes. Providers and caregivers are happy to have more help through the waivers.
- Some people on waivers thanked their case managers and support brokers for being helpful and easy to reach. They like that case managers are there for them and help guide them through waiver services. It sets the tone for what strong case management should look like all over the state.
- Providers like the training videos from the Cabinet about new regulatory changes. They would like to see more of them in the future.
- People said that they like the community integration services. The services allow people on the waivers to be a part of the local community. These services can help people to work outside their home or to spend time with neighbors, family and friends.
- Many providers shared that monitoring and communication from DMS, DAIL and DBHDID has gotten better in the past year. Providers noted that these groups work well to support good services.
- People like hiring family members through participant-directed services. They see this as an important part of their waiver services.

In Figure 1, we show the comments that were shared most often in the focus groups. These are the areas where DMS can improve.

Figure 1. Overview of Top Comments



Below, we describe each theme and the information gathered in the focus groups.

2.1 Improve communication from the Cabinet about waiver programs:

The theme that was brought up most in the focus groups was the lack of communication. This causes confusion around the waivers. People have trouble reaching the right person to answer questions. They said it is difficult to reach someone who can help and takes too many steps. Also, people said they get different answers to the same question from different Cabinet staff. Providers said that it is tough to get a clear answer from the Cabinet. This makes it challenging to follow the program rules. Providers want to get more updates and information from the Cabinet.

2.2 Current waiver payment rates make it hard for providers to provide better service and find good staff:

Focus group members shared payment rates are too low and not equal across waivers. They think this makes it hard to improve programs. Some providers said that there has not been a rate increase in many years. Others said that pay is too low for the work that goes into their business and the paperwork required by the Cabinet. Also, providers have a hard time finding good staff. People choose to work in other jobs that pay better, like fast food, or jobs that require less training. This makes it difficult to find and keep the best workers. People affected by the waivers talked most about the personal care rate for the Home and Community Based (HCB) waiver. People indicated that very few staff will provide personal care services because the rate is too low.

2.3 It is hard to find waiver services and providers:

Many people said that it is tricky to find providers for waiver services. This is a more significant issue in rural areas where common services are not provided. Other services that are difficult to find are home delivered meals, certain therapies and community supports.

The list of providers given to people on waivers has old or incorrect information and makes it more difficult to know which providers can help with services. There are services that providers won't offer because they believe it is too troublesome to do what the regulations say to do.

2.4 Improve Medicaid Enrollment Process:

People encounter problems when they apply or renew their Medicaid coverage. This can cause them to lose Medicaid eligibility. Many providers will continue to serve people with a gap in Medicaid coverage. This leads to the provider losing reimbursement.

People stated that they have issues with eligibility paperwork getting lost. Many do not know the paperwork needed to renew each year. They shared that they do not think they get good answers from the local offices. People who were denied Medicaid coverage often did not know why they were denied. People do not like the number of letters they get from "Medicaid." They often do not understand what the letters are saying. Staff helping with the Medicaid application process said that the process never goes smoothly and that they expect mistakes and confusion.

2.5 Improve the process of finding workers for participant directed services (PDS):

People shared that finding a PDS employee costs a lot of money and takes too long. Many waiver recipients cannot afford to find staff and get the needed background checks. They stated that some steps in the process are not needed. They noted that a PDS employee's background check should be able to be used for multiple PDS jobs. Others on waivers think the paperwork they must fill out is difficult to follow. They asked for more tools to help families ensure the paperwork is correct. There is concern that people on the waivers who choose PDS do not know what is expected of them when they choose PDS over traditional services. People need more help from their support broker to make a good choice. Recipients asked for providers and case managers to do more in this process to make sure they are getting good care. People stated that the lack of help leads to more fraud, waste and poor care, which many think is a challenge with PDS.

2.6 Make access to transportation services better, and change waiver rules:

Focus group members stated that transportation is important. Transportation is one of the most difficult services to locate and use in the community. Limited waivers offer this as a paid service. People believe these services should be offered in all waivers. Those with access to transportation do not like that the services are not always available when they need it. Recipients stated they still miss doctor visits and other appointments. Those on waivers asked for more support to plan trips due to transportation challenges. For example, individuals noted that it is difficult to schedule a pick up. People do not like when they can't get transportation because someone in their home owns a car. This does not mean that the person with a car can or will provide a free trip to the recipient.

2.7 Make assistance from Carewise and Medicaid Waiver Management Application (MWMA) more accessible and the processes more user friendly:

Carewise is the company that helps DMS review and make decisions on things like level of care and approving person-centered plans of care. MWMA is the computer system that is used to house the processes for waiver eligibility and service plans.

Many people said they do not think that the MWMA system works well. They stated that they do not believe Carewise is making correct decisions. It is difficult to get approved for enrollment and services. Focus group members shared:

- Participants were put in the wrong waiver in MWMA. This caused a loss in services for a period of time.
- Providers have issues getting answers from the MWMA support desk or Carewise. They tend to blame each other for a problem instead of fixing it.
- Providers indicated that they have difficulty contacting the MWMA Help Desk and Carewise staff. They further shared that call volumes are high and hold times are long.
- Many providers want access to MWMA so they can communicate more with case management providers and DMS.

2.8 Improve the waiver rules to be clear across all waivers:

Providers want waivers to be clear and consistent across waivers. Focus group members stated that the waivers are too confusing. The amount of “gray area” in how waivers are written has led to recoupments that providers did not expect. Using different guidelines for the same service is confusing. This affects providers working with more than one waiver program and for those on waivers and caregivers when they switch programs. People talked about rules they believe are not fair and do not allow recipients access to the services they want. An example of a rule noted to be unfair was the 40-hour cap on services on the Michelle P waiver.

2.9 Improve the waiver knowledge for people at the Cabinet and direct care workers, to improve programs and the quality of care for people on waivers:

Many people believe that the Cabinet and provider staff need to know more about disabilities and waiver programs. This will help them to serve people on the waivers who have many complex issues. Providers would like more trainings about cases with more than one diagnosis. Also, more trainings for behavioral health and acquired brain injury would be helpful. Providers stated that there is not enough assistance and training offered by the state. This makes it difficult for providers to keep their staff trained. Staff training has a high cost and high risk for providers since staff do not always stay in their job for long. Other providers indicated that there is too much training which takes them away from day-to-day work.

2.10 Improve how providers work together:

People would like to see better coordination between Medicaid services and other programs. This includes, but not limited to, public school systems. Several families stated it was challenging when their child moved out of the public school system into adult waiver services. Many people had issues with these changes. They had not made plans for losing school support. Other people indicated that they want their doctors and waiver providers to work together for better healthcare outcomes. It is hard for people to keep up with parts of their care like understanding doctor’s orders and getting prescription drugs.

Conclusion:

At the end of the focus groups, participants thanked DMS and Navigant for listening to the comments about the waiver programs. They shared that they hope the changes that are made are helpful and make the programs better. People affected by the waivers want more chances to share their thoughts and talk about their concerns. The Commonwealth promised to include the public more and have more regular meetings. DMS pledged to include the thoughts and concerns of the public when planning any changes for HCBS waiver programs.