The Commonwealth of Kentucky Department of Medicaid Services (DMS) contracted with Navigant Consulting Inc. (Navigant) to assist with the evaluation, improvement and ongoing support of Kentucky’s 1915(c) waivers. Recognizing that a comprehensive assessment includes feedback from stakeholders, the Commonwealth held focus groups across Kentucky in the fall of 2017 with stakeholders and structured the groups as follows:

- Participants
- Caregivers
- Direct support professionals
- Providers

The intent of the focus groups was to engage and receive stakeholder input on the current state of home and community based service (HCBS) delivery through existing waivers, to better understand how waivers are working now, including what aspects are working well and what could be made better. A focus group was conducted with each stakeholder group mentioned above, in 10 sites across the Commonwealth, for a total of 40 focus groups. Nearly 500 participants attended across the Commonwealth. In this report, we summarize the themes stakeholders raised most frequently during the focus groups.

This report is intended to be a resource for the Kentucky Department of Medicaid Services (DMS) to respond to past concern expressed by stakeholders that their input did not adequately factor into policy and design decisions. Additionally, stakeholders reported that they were unaware of how their feedback had been handled in the past and requested transparency to ensure feedback was clear and not misinterpreted. Therefore, the purpose of this summary is to report the findings collected from the focus groups and promote transparency to stakeholders throughout the assessment process.

**Top Focus Group Themes:**

Overall, Navigant heard numerous comments from various stakeholders across the Commonwealth that are vitally important to the improvement of the HCBS programs. While discussing opportunities for improvement, stakeholders also voiced strengths of the waiver programs that they wish to see reflected in any re-design. Some of the strengths highlighted include:

- Many stakeholders voiced their appreciation for the waiver services and credited them for improving the quality of life of waiver recipients. Stakeholders shared appreciation to the waivers for allowing participants to stay in their homes and gain independence. Providers and caregivers expressed their enjoyment in seeing the progress of participants’ conditions since being a waiver participant.

- Some participants complimented their case managers and support brokers for being very knowledgeable and readily accessible. Stakeholders satisfied with their case management often described the services as consistent, reliable and helpful in navigating HCBS delivery, and setting the tone for what universal, high-quality case management should deliver statewide.

- Stakeholders indicated that the webinars released by the Cabinet addressing new regulatory changes are helpful and stakeholders wish to see more of them released in the future.
Stakeholders indicated that community integration is a beneficial service that allows waiver recipients to be a part of their community through various activities, such as volunteering and encouraging social interactions with fellow waiver recipients.

Many providers indicated that despite frustrations, they believe that the tone of monitoring and communication from DMS and operating agencies has improved in the past year, and is more collaborative and less punitive in nature.

Stakeholders expressed their appreciation for being able to employ family members through participant-directed services.

Based on the comments received from the focus groups, 10 key themes have been identified for areas of improvement, as summarized seen in Figure 1.

**Figure 1. Overview of Key Themes**

- **Communication**
  - Improve communication from the Cabinet (DMS, DBHDID, DAIL, and DCBS) about waiver programs

- **HCBS Payment Rates**
  - Establish sound rates that reflect provider agency costs that are equitable across waivers

- **Network Adequacy**
  - Address the lack of service access and network adequacy across a variety of HCBS service types

- **Eligibility and Recertification**
  - Improve clarity and communication during the eligibility and recertification process

- **Participant Directed Services (PDS)**
  - Enhance the process of hiring participant directed services (PDS) employees, as well as ability to recruit high quality employees

- **Transportation**
  - Expand access to transportation, and revise regulations to promote access to paid providers

- **MWMA and Carewise**
  - Address challenges the Medicaid Waiver Management Application (MWMA), including its interface with Carewise

- **Regulation Interpretations**
  - Apply consistency and clarity in regulations across waivers

- **Internal Training**
  - Expand clinical and technical knowledge within the Cabinet and among the direct care workforce, to enhance quality of care

- **Care Coordination**
  - Improve collaboration and transition of care for current and prospective waiver recipients

In the section below, a detailed description of each theme is provided with the information we collected from stakeholders.

2.1 **Improve communication from the Cabinet about waiver programs, including more frequent information sharing, and more accurate, consistent delivery of information across departments:**

Overall lack of communication and miscommunication were the most frequently reported issues in focus groups. Participants reported difficulty getting in touch with the proper contact for resolving specific issues, stating that reaching someone who could offer assistance was often a frustrating, multi-step process. Additionally, focus group attendees reported receiving varying answers to the same question from different contacts within the Cabinet. Providers indicated that the key factor in regulatory non-compliance, resulting in recoupment, is the difficulty in getting consistent information. Providers requested timely, recurring updates that clearly outline the needed information to promote regulatory compliance.
Many participants also reported that they would like to see better communication between all the parties involved with their care (i.e. doctors, case managers and providers).

2.2 Current HCBS payment rates limit providers’ ability to improve quality, including attracting high-quality workforce to improve service delivery:

Focus group attendees believe reimbursement rates are not adequate or equitable, which they suggested affects the quality of care that can be provided. Several providers reported that they had not had an increase in rates in several years, others indicated that pay is too low considering the high volume of administrative and documentation required. In addition, providers noted difficulty competing with other industries for direct care staff, such as the fast food industry or industries that require less training and skills but offer higher pay. In turn, service delivery has been negatively impacted, with shortages of adequately trained employees since trainings are costly and turnover is high. The rate most recently cited by participants is the personal care rate for the Home and Community Based (HCB) waiver, which stakeholders universally described as inhibiting network development and the ability to recruit staff.

2.3 Dissatisfaction with lack of service access and network adequacy across a variety of HCBS service types:

Another common theme that emerged from focus groups was gaps in network adequacy. Attendees frequently cited lack of providers in rural areas and lack of specialized/expertise services as issues. Other common concerns specific to network adequacy included difficulty in receiving necessary services such as home delivered meals, specialized therapies, community supports, and having outdated or inaccurate information in the provider directory. Additionally, participants noted that they have encountered providers that are unwilling to render all of the services approved in a participant’s service plan, or were hesitant or unwilling to offer certain services due to the associated monitoring risks and frequent recoupments associated with delivery of a service.

2.4 Improved clarity and communication during the eligibility and recertification process:

Attendees frequently reported challenges navigating annual eligibility, frequently citing instances when individuals experienced a lapse in coverage during this process. Many providers indicated that they continued to serve these recipients, experiencing financial losses to minimize disruption in service delivery to vulnerable participants. Several providers indicated losses of several thousand dollars in the past year.

Waiver participants and their caregivers complained that their applications were lost and struggled to receive direct answers to their issues, including what documentation was needed to complete an application. Similarly, those who were denied coverage could not receive a clear answer as to why they were denied. Overall – the volume and clarity of notices from Medicaid was cited as an issue. Those who participate in the eligibility and redetermination process, including professionals who assist participants and their families to navigate required procedures, advised that they expect confusion and disruption and chronically experience negative experiences each year. There is high demand among stakeholders for DMS to collaborate with the Department of Community Based Services (DCBS), as both agencies play a role in these processes.
2.5 Improve the process of hiring participant directed services (PDS) employees, as well as ability to recruit high quality employees:

Attendees indicated that the process of hiring a PDS employee is costly and time consuming, many waiver participants indicated they struggle to manage the costs of recruiting and obtaining required background checks. There were complaints of inefficiencies, such as requiring the same PDS employee to obtain the same background check for each participant they work with within a finite period. Other participants reported that documentation associated with the process is difficult for families and recommended having resources in place to help families accurately complete the application. Similarly, many attendees expressed concern that participants who elect the PDS model lack adequate education when choosing the PDS service delivery model, so need more assistance from their support broker to navigate the process. The stakeholders suggested additional oversight from providers and case managers to ensure adequate care of the waiver participant.

2.6 Improve access to transportation, and revise regulations to promote access to paid providers:

Focus group attendees frequently cited transportation as a primary challenge to community based living. Transportation is offered only under certain waivers, and stakeholders believe transportation services should be available across all waivers. Those with access to transportation services suggested services are unreliable, causing missed physician appointments and other disruptions. Stakeholders would like to see better linkage between HCBS waiver operations, and non-emergency transportation services offered within the Medicaid system. Participants indicated more logistical support is needed, such as guidance on what stop to use on the bus or where to go when exiting the bus. Many were frustrated that transportation services are denied when someone in their home owns a car, as this circumstance did not preclude individuals from needing day-time support. Finally, attendees voiced concerns that transportation is billed to one participant, regardless of whether other participants received transport within the trip.

2.7 Difficulty with the use of the Medicaid Waiver Management Application (MWMA), particularly with Carewise:

The operational processes of MWMA and Carewise were frequently cited as inefficient and the source of challenges with eligibility and issuance of prior authorization. Among the concerns:

- Participants reported miscoding in MWMA, leading to an interruption in their services.
- Carewise placed waiver participants in the incorrect waiver, disrupting services.
- Providers indicated difficulty in getting solutions from the MWMA support desk and/or Carewise who pin solution on the other party, resulting in ongoing churn.
- Stakeholders reported having issues contacting both MWMA and Carewise due to high call volumes and extended wait periods. Those that get through have encountered a lack of knowledge among answering parties, and often have their call transferred several times before reaching a knowledgeable staff member.
- Many providers would like more access and use within MWMA to communicate in a timely fashion with case management providers and DMS.
2.8 Improved consistency and clarity in regulations across waivers:
Providers want waivers that are concise and clear, and find the current waivers and regulations burdensome and subject to individual interpretation. This regulatory "gray area" has led to challenges with audits and unanticipated recoupments. Varying definitions for the similar elements between waivers is confusing, both for providers serving multiple waiver programs, as well as for participants and caregivers navigating transitions from program to program. Stakeholders pointed to arduous regulations they believe are not helpful and adversely impact certain groups or only select waivers, such as the standard 40-hour cap on services used on the Michelle P waiver.

2.9 Improved clinical and technical knowledge within the Cabinet and among the direct care workforce, to enhance programs and the quality of care waiver recipients receive:
Multiple stakeholders expressed the need for Cabinet and provider staff members with deeper expertise in disabilities and HCBS programs, so that these staff members would be better able to respond to increasing complexity and acuity in the participant population. Stakeholders would like to see more subject matter expertise related to dual-diagnosis, behavioral health and acquired brain injury, among other elements. Providers indicated that the challenge of maintaining well-trained staff stems from both current payment rates, and inconsistent technical assistance and training practices across waivers. Training for specialized staff members is expensive and a gamble for providers because of high staff turnover rates. While some stakeholders expressed concern about a lack of training, others complained of too much training that took them away from day-to-day responsibilities.

2.10 Improved collaboration and transition of care for current and prospective waiver recipients:
Coordination with non-Medicaid systems and transition of care for waiver recipients was highlighted as an unaddressed issue across all waivers. Focus group attendees specifically mentioned the difficulties encountered transitioning youth out of the public-school system into adult services. Many participants and their caregivers struggled to adjust and had not proactively planned when aging out of eligibility for school-based supports, essentially falling off a cliff with no planning or education. Other stakeholders called for better coordination across their healthcare and long-term care services and supports (LTSS) providers. Participants noted that there was a lack of coordination among Medicaid providers (including providers of non-waiver services), resulting in confusion and inefficient care delivery.

Conclusion:
At the end of the focus groups, stakeholders voiced their appreciation to the Commonwealth for including them in the waiver assessment and are hopeful for upcoming program changes. Stakeholders also seek more opportunities to address future concerns. The Commonwealth is committed to further stakeholder engagement and communication. DMS intends to carefully consider stakeholders’ feedback during its ongoing assessment of HCBS waiver programs.