



Children’s Waiver Feasibility Study Focus Group Summary Report

Background

The Cabinet for Health and Family Services (the Cabinet) is currently leading a study to determine whether it would be possible to develop a Medicaid home and community-based services program for children with the following conditions, who meet the institutional level of care.

- Severe emotional disability (SED)
- Intellectual disabilities and related conditions (ID/RC)
- Autism spectrum disorder (ASD)

As part of this study, from late May to early June 2023, the Cabinet, in partnership with the consulting firm, Guidehouse, hosted focus groups with people receiving home and community-based services, people on waiver waitlists, family members, caregivers, and advocates.

The purpose of these focus groups was to learn more about the needs of children, identify where there may be gaps in services and supports, and to discuss potential solutions that could help meet these children’s needs.

Focus Group Methodology

The Cabinet traveled to eight areas of the State to reach as many people as possible.

Table 1: Focus Group Locations

Location	Date
Lexington	May 22, 2023
Somerset	May 23, 2023
Prestonsburg (virtual)	May 24, 2023
Florence	May 30, 2023
Louisville	May 31, 2023
Frankfort	May 31, 2023
Owensboro	June 1, 2023
Bowling Green	June 1, 2023
Virtual Group for Advocates	June 5, 2023

The Cabinet limited the number of participants to a maximum of 15 per session to give each participant an opportunity to provide their comments throughout the discussion. To accommodate as many individuals as possible, the Cabinet offered evening focus groups and hosted two focus groups at the same time in some locations. Metropolitan locations had a higher turnout of individuals at these focus groups. In addition, the Cabinet sent a participant

survey with similar questions to get the feedback of those who were not able to attend in person. Representatives from the Department for Medicaid Services, Department for Behavioral Health, Developmental and Intellectual Disabilities, and the Department for Aging and Independent Living attended all the focus groups.

The Cabinet appreciates the attendance of all the individuals who participated in the focus groups and values their feedback. This report reflects the collective themes from the in-person focus groups.

Focus Group Themes

Guidehouse facilitated each focus group and asked participants the following core questions:

1. What are some services that you would like to see covered under a potential new program for children with SED, ID/RC, and ASD?
2. What does Family Support and Training need to include to be helpful to you?
3. What would make it possible to use Respite services?
4. What are some of the barriers you and/or the child you care for have experienced or are currently experiencing in terms of receiving the care needed?
5. What are some potential solutions that might address observed barriers?

Guidehouse allowed for open discussion at the end of each focus group to allow participants to ask questions and raise topics of interest to them that may not have been discussed. Table 2 highlights the services suggested by focus group audiences. **As a reminder, these are only service suggestions from the focus groups. No decisions about what would be offered in a potential new waiver have been made.** The asterisks indicate that the service was mentioned in several focus groups.

Table 2. Summary of Suggested Service Offerings

Theme	Description
Attendee-Suggested Service Offerings in a Potential New Waiver	
Specialized Therapies	<ul style="list-style-type: none"> • Art therapy • Behavioral therapy * • Equine therapy • Extended Physical, Occupational, and Speech therapy (beyond what Medicaid State Plan covers) * • Feeding therapy • Hydrotherapy * • Massage therapy • Music therapy • Vision and orientation therapy
Other Long-Term Services and Supports	<ul style="list-style-type: none"> • Advocacy services * • Center-based respite • Community Living Supports, which includes training in activities of daily living and instrumental activities of daily living, community activities, relationship building and socialization *

Theme	Description
	<ul style="list-style-type: none"> • Crisis intervention hotline and services * • Gene sight testing • Home safety assessment and education * • Relationship building skills • Residential services, such as Bridge the Gap Addiction and Mental Health Services in Louisville • Specialized day care * • Summer camps for children with special needs * • Supported employment * • Swim lessons with special instructor * • Targeted case management * • Transition programs from high school to college, such as Western Kentucky's Transition to Work and Independent Living Program *
Equipment	<ul style="list-style-type: none"> • Harness • Laminators • Outdoor swing • Sensory beds • Sensory socks • Sensory supports * • Therapy tools and emotional posters • Weighted blankets
Assisted Technology	<ul style="list-style-type: none"> • AngelSense Tracker • Augmentative and Alternative Communication Device * • iPads with special applications * • Trainings for parents on how to use purchased Assisted Technology
Supplies	<ul style="list-style-type: none"> • Diapers * • Enemas • Gas Drops • Melatonin • Pedialyte * • Pediasure * • Probiotics • Motrin • Tylenol • Vitamin D • Wipes *
Home and Environmental Modification	<ul style="list-style-type: none"> • Alarms • Cameras • Key coding the house (for elopers) • Outdoor fencing (for elopers) * • Vehicle modification

Theme	Description
Other Services	<ul style="list-style-type: none"> • Service animal • Transportation or gas costs *

Importance of Family Support and Training

In all the discussion groups, focus group participants noted the lack of specialized trainings available to families with children with SED, ID/RC, and ASD. They stated that these trainings are important, particularly when a child is first diagnosed and families are feeling lost, confused, and overwhelmed. Table 3 lists the types of training and supports that participants noted would be extremely helpful to parents. The asterisks mark those trainings that were mentioned in multiple focus groups.

Table 3: Family Support and Training

Requested Family Support and Training	
Training for Parents of a Child with a New Diagnosis	<ul style="list-style-type: none"> • Home safety education (e.g., guns, medications) * • Training on how to navigate the system and apply for programs * • Training on the array of services available through Medicaid State Plan and waivers • Training on the specific condition of the child and what to expect * • Monthly trainings for parents and family members on different waiver topics, such as person-centered planning and goals discussion
Medical Training for Parents	<ul style="list-style-type: none"> • CPR and First Aid Training * • Specialized Medical Training (e.g., G tube feedings, transporting children with oxygen) *
Other Practical Caregiving Trainings	<ul style="list-style-type: none"> • Training on how to manage a child who is having a violent outburst * • Training for parents on how to be better advocates for their children • Trainings on guardianships and transitioning services * • Trainings on estate planning • Mentorship program to shadow families with similar issues • Training on how to bathe a child with dignity
Support for Siblings and Other Children Living in the Same Home	<ul style="list-style-type: none"> • Trainings for siblings on how to handle certain situations • Counseling services for siblings * • Sibling support programs, like those offered by Children’s Hospital *
Educational Materials and Applications	<ul style="list-style-type: none"> • Welcome packet and road map for parents of newly diagnosed • One Stop Shop for information and resources • An app with a repository of workers who are trained to work with children with SED or ASD
Mental Health Services	<ul style="list-style-type: none"> • Counseling sessions with provider of choice * • Support groups for parents *

Respite

Although many focus group participants stressed the importance of respite programs, several attendees noted that it was difficult for them to access respite services. Their reasons included the high turnover of direct service workers and the lack of trainings available for respite workers, such as how to manage a child who may have violent outbursts.

Several participants noted that the low pay rate prevents agencies from maintaining direct service workers and that respite workers should be paid “a competitive wage” with financial incentives. Some noted that the payments for workers should be the same across the different existing waivers. Several participants also stated that there should be specialized trainings for respite workers on safety measures, trauma informed care, implicit bias, and CPR certification. Further, families suggested more guidance from the Cabinet on how to use participant-directed services, as well the development of a database of trained participant-directed service workers.

They also stated that it would be helpful to have a center-based respite for multiple day stays. They highlighted the importance of specialized day care, after school programs, as well as camps during the summer months to provide recreational activities, socialization, and specialized care to their children.

Additional Themes

There were several other themes that emerged from the focus groups.

Focus group participants seek increased communication from the Cabinet and education about Medicaid services for the broader public.

Focus group participants stated that they primarily receive information about Medicaid waivers through word-of-mouth and parent advocacy groups, including online forums such as Facebook and desire more information directly from the Cabinet via improved marketing and communication.

Focus group participants shared that they have limited to no access to benefits counseling and/or communication with a designated case manager.

Many participants stated that they are unaware of all the services and benefits that are available to their child through the waivers, including those in the broader Medicaid state plan and non-Medicaid services. They stated that it would be helpful to have advocates and improved points of entry to help them navigate the system. Several members also stated that they do not engage in person-centered planning or goals discussion with their case managers and recommended the Cabinet review and enhance Case Manager training.

Participant Directed Services are considered essential and allow for much needed care for a child with SED, ID/RC, and ASD. Focus group participants strongly advocate for legally responsible individuals to serve as self-directed employees.

Several focus group participants stated that they had to give up their jobs to care for their child because there are no other individuals who understand the child and know how to provide care

Participants suggested the following resources would be helpful to families of a child with SED, ID/RC, and ASD:

- One Stop Shop for information and resources staffed by knowledgeable and compassionate individuals
- Simplification of the application and recertification process
- Repository of all resources
- Services roadmap
- Services guidebook
- An updated listing of providers who accept Medicaid

to the child. Other focus group participants expressed their fear of leaving their vulnerable or non-verbal child with an unknown individual where any adverse outcomes may not be easily conveyed by the child. Several participants also noted the difficulty in finding a worker to provide care for a child with behavioral issues or who requires specialized behavioral management techniques.

Focus group participants also advised that it would be helpful to have a database with information on participant-directed services workers who have been screened and approved by the State and are available to provide services (akin to care.com).

It is critical to provide children with SED, ID/RC, and ASD with intensive supports and services earlier in their lives to have the most impact and positive outcome on their development.

Families with children on the waiver list emphasized the importance of providing intensive services early in life. They expressed concern that they were “losing time” as they waited for waiver services and that the long wait to be assessed and approved for waiver services would have a negative effect on their child’s development later in life.

Key Takeaways

The focus groups provided key takeaways for the Cabinet to consider as they explore a new waiver for children with SED, ID/RC, and ASD.

Case management in a children-focused program will need to be designed to specifically address the unique needs of children with SED, ID/RC, and ASD and their caregivers.

The focus groups highlighted the need for specialized training on the target population for case managers to help family members navigate the system, advocate for the family, and provide information on the array of services that are available to the child, including state plan services, EPSDT, and services available across different agencies.

The service offerings of a potential waiver need to be comprehensive to meet the distinct needs of children with SED, ID/RC, and ASD, with a focus on specialized therapies and behavioral supports / counseling.

Parents of children with SED stated that they needed crisis hotline and crisis intervention services. Currently they are forced to take their child to the hospital in crisis situations.

Parents of children with ASD discussed the importance of communication devices, sensory items, such as weighted blankets and vests, group socialization and home modifications to help keep those children who elope safe at home. They also mentioned the need for access to early intervention behavioral supports to have the most impact on their child’s development.

Parents of children with ID/RC discussed the importance of programs and supports that would allow individuals to reach the highest level of independence, such as job preparedness programs and supported employment.

Parents of all children emphasized the importance of specialized therapies, as well as specialized day care and respite programs. Parents stated that it would be helpful to have a waiver for children pay for over-the-counter items like Pedialyte, probiotics, and diapers, which are necessary items for their child, but can be quite costly.

A service package for a potential children’s waiver needs to consider the whole family.

A child’s diagnosis undoubtedly has impacts on the entire household. Therefore, focus group participants said a children-focused program should also provide resources and supports to family members, such as counseling services and trainings for siblings.

Early planning and options counseling is crucial for children receiving waiver services to ensure that there is no disruption of services when they reach the maximum age for the program and transition to adult services.

Focus group participants stated that planning should begin several years before the age of 21 and the importance of case managers to guide them through this process. Further, many parents mentioned that it would be helpful to receive information on guardianships and power of attorneys.

At all eight focus groups, participants stated that they feared what would happen to their child once they passed away. Several participants suggested the need to explore residential services for these children after the age of 21. All focus groups stated that these children should have automatic and seamless transition to another waiver serving adults.

The Cabinet will need to support and equip the existing provider network to offer services through a new children’s waiver. This may necessitate exploring network expansion strategies.

Focus group participants whose children are already receiving waiver services stated that they are on waitlists to see certain providers, such as Applied Behavioral Analysis Therapists and Speech Therapists. Focus group participants said that if the Cabinet moves forward with a new waiver for children with SED, ID/RC, and ASD, it will not only be important to offer services, but to ensure that individuals can access these services. Suggested strategies to improve access included:

- Reviewing the rates for providers
- Giving financial incentives to providers for serving in areas identified as hard to reach
- Expanding the pool of eligible providers

Questions

Any questions about this report can be directed to CHFS.HCBSWorkGroup@ky.gov.