

# Report of the Special Committee on Intellectual and Developmental Disability Waiver Modernization to the 2023 Kansas Legislature

**CHAIRPERSON:** Representative Will Carpenter

**VICE-CHAIRPERSON:** Senator Richard Hilderbrand

**OTHER MEMBERS:** Senators Molly Baumgardner, Tom Hawk, Carolyn McGinn, and Mike Thompson; and Representatives Barbara Ballard, John Barker, Bill Clifford, Brenda Landwehr, and Susan Ruiz

## **STUDY TOPIC**

The Committee is directed to:

- Review and recommend options to modernize the Intellectual and Developmental Disability (I/DD) Waiver and its structure in an attempt to address the I/DD Waiver waitlist and workforce struggles and utilize a working group structure similar to the 2021 Special Committee on Kansas Mental Health Modernization Reform that is facilitated by an independent third party organization. [*Note:* The Legislative Coordinating Council authorized the Special Committee on Home and Community Based Services I/DD Waiver to meet during the 2021 Interim. Utilization of the working group structure was one of that committee's key recommendations.]



# Special Committee on Intellectual and Developmental Disability Waiver Modernization

## REPORT

### Conclusions and Recommendations

The Special Committee on Intellectual and Developmental Disability Waiver Modernization (Committee) generally agreed the State should pursue a Community Support Waiver (CSW). Therefore, the Committee recommends:

- The Kansas Department for Aging and Disability Services (KDADS) provide a fiscal impact statement for each service discussed by the Committee for possible inclusion in the CSW;
- A \$20,000 annual individual cap be placed on the CSW;
- The Executive Branch transition the Medicaid managed care system from a 1115 waiver to a 1915(b) waiver;
- KDADS provide an estimate on the number of individuals likely to request self-determination;
- The Kansas Department of Health and Environment (KDHE) and KDADS continue to study strengths-based assessments, such as the Supports Intensity Scale or the Medical Functional Eligibility Instrument (MFEI), as alternatives to the deficit-based BASIS assessment tool for the Home and Community Based Services Intellectual and Developmental Disability Waiver, with the acknowledgment that the University of Kansas is still working on the financial portion of the MFEI assessment used to determine funding levels;
- The CSW include individual budget authority across all services; and
- KDHE and KDADS identify a process to prevent children from being removed from the Autism Waiver proposed recipient list without notification.

*Proposed Legislation:* None.

### BACKGROUND

The 2021 Special Committee on Home and Community Based Services (HCBS) Intellectual and Developmental Disability (I/DD) Waiver included a recommendation in its report to the 2022 Legislature that the Legislative Coordinating Council (LCC) consider approving a task force or

committee, with a similar structure to the 2020 and 2021 Special Committees on Kansas Mental Health Modernization and Reform, to study modernization of the HCBS I/DD Waiver. The Chairperson of the 2021 Special Committee on HCBS I/DD Waiver requested the LCC appoint a 2022 interim committee to review and recommend options to modernize how the I/DD waiver could

be restructured in an attempt to address the I/DD waiver waitlist and the workforce struggles, and further requested authorization to utilize a working group structure similar to the 2021 Special Committee on Kansas Mental Health Modernization and Reform, to be facilitated by an independent third-party organization.

The Special Committee on I/DD Waiver Modernization (Committee) was granted three meeting days by the LCC and met September 28, October 13, and November 1, 2022, at the Statehouse.

## COMMITTEE ACTIVITIES

The Committee's three meetings focused on an overview of national and other states' information regarding modernizing the HCBS I/DD Waiver; public testimony regarding concerns of the I/DD population; input from Roundtable members on areas to be addressed to meet the needs of the I/DD population; and a review of proposed items for inclusion in a Community Support Waiver (CSW) provided by Roundtable/Working Group members for the Committee's consideration.

### September 28 Meeting

#### *Background Information*

At the September 28 meeting, the Committee received background information on the HCBS I/DD waivers employed by each state, the services provided to the I/DD population, the authorizing section of the Social Security Act, and each state's waitlist from Kansas Legislative Research Department (KLRD) staff. KLRD staff also provided in-depth information on the purpose, eligibility requirements, and waitlist for I/DD waivers in select states recommended for further review by InterHab, the Kansas Council on Developmental Disabilities (KCDD), the Kansas Department for Aging and Disability Services (KDADS), and other stakeholders. Additionally, KLRD staff provided a document tracing the history of the Kansas I/DD waitlist from January 2013 to July 2022 and HCBS I/DD Waiver expenditures for FY 2012 to FY 2023.

### *State I/DD Waiver Modernization Considerations*

A representative of the Kansas University Center on Developmental Disabilities (KUCDD) and the State of the States in Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance reviewed national information regarding modernizing the HCBS I/DD Waiver, including funding data over the past 35 years for individuals in institutions and in community settings, and families providing for such individuals. The representative said most data cannot be relied on, since only 20 percent has focused on state support rather than providing a broad spectrum of information, and data varies from state to state and does not fully represent funding issues for I/DD. The representative noted the best way to draw conclusions from data is, over the years, to be aware of the shifts in focus and identify innovations.

The KUCDD and State of the States representative provided a State of the States Kansas Profile, including the number of individuals with I/DD living with family members, the number of those living with aging caregivers, and public I/DD spending for services.

### *Nationwide Overview and Trends in I/DD Waiver Programs*

A representative of the National Association of State Directors of Developmental Disability Services (NASDDDS) provided information on national trends related to I/DD waivers. The representative noted, nationwide, 85 percent of individuals with I/DD and 59 percent of recipients of long-term supports and services live with family, noting the reliance on aging family caregivers (caregivers aged 60 and older) should be considered. In Kansas, 72 percent of individuals with I/DD receive services in their homes, with 24 percent of these individuals living with aging family caregivers.

The NASDDDS representative noted the lack of a model or pattern for state support in the I/DD Waiver because agencies are diverse in structure and varied in service delivery, with Medicaid being the primary source for both health care and long-term services. The representative noted the main challenges involving the I/DD population are the workforce shortage, waitlists, data availability and utilization to inform policy direction, and

providing support for individuals with complex needs. The representative's presentation also included an explanation of the CSW, common objectives, and the essential steps for Medicaid authority development. The NASDDDS representative recommended the Committee include all stakeholders in designing and modifying a waiver program.

The NASDDDS representative provided the following additional information in response to Committee member requests: a workforce availability report, state initiatives on using federal American Rescue Plan Act funding to address workforce issues, wages for direct support workers across states, and benefits provided to direct support workers.

### ***History of Kansas I/DD Waiver Modernization Efforts and Kansas-specific Considerations***

A representative of KCDD reviewed the history of the I/DD Waiver in Kansas from 1974 to the present and highlighted innovative efforts and initiatives to change the I/DD system, such as Employment First legislation, Supports and Training for Employing People Successfully (STEPS), and the Jim Porter Transition work group.

The KCDD representative noted a need for a better strengths-based assessment tool, such as the Supports Integrity Scale (SIS), to replace the currently used, outdated, and deficit-based BASIS assessment tool. The representative stated most Kansans with disabilities are not known to the system and noted the proposed comprehensive study of the I/DD Waitlist by the KUCDD will help identify the needs of those on the waitlist. The representative noted nearly all individuals with I/DD are capable of working when provided appropriate supports; however, improving the reimbursement rate for supported employment is a key factor in addressing workforce issues. Kansas reimbursement for supported employment is \$12 per hour, and some states reimburse at \$40 per hour.

The KCDD representative provided a list of states that eliminated sub-minimum wage rates and the legislation used to accomplish that.

### ***Presentations from Individuals, I/DD Service Providers, and Local I/DD Advocacy Groups***

The Committee heard presentations from private citizens and two local I/DD advocacy groups: InterHab and the Disability Rights Center of Kansas.

The private citizens discussed the following issues: the lack of services for individuals with complex needs; the harmful effects of the waitlist; the community service failures of the HCBS I/DD Waiver and the need for institutional services for profoundly disabled individuals; the lack of day services, crisis funding, respite care, and other supports; the inconsistency and lack of safety in transportation services; the embarrassment caused by and need to replace the BASIS assessment tool currently in use, which was seen as "disrespectful"; the need for a consumer-directed CSW with individual budget authority, increased wages for case managers, annual cost-of-living adjustments and behavior supports; the failure to provide notification when a child is removed from the Autism Waiver proposed recipient list; the denial of durable medical equipment and the barriers of the appeal process; and the need for community living choices for individuals with I/DD.

The I/DD advocacy groups noted the lack of a strong network of community-based supports for persons with I/DD; the need to further the promise of the Kansas Developmental Disabilities Reform Act by providing financial adequacy and certainty, offering service alternatives, meeting the complex needs of some individuals, and utilizing locally driven planning to address the waitlist; recommendations regarding person-centered and family-centered CSWs, improved care coordination by KanCare managed care organizations (MCOs), service cost estimates for these waivers, individually directed goods and services, and the use of assisted technology; the waitlist's blocking of support for medically and intellectually needy individuals; and the need to move from the BASIS assessment to the strengths-based SIS assessment.

### ***Roundtable Introduction and Committee Directions***

Kansas Health Institute (KHI) staff noted Roundtable participants would serve as a resource

for Committee members by assisting in the development of comprehensive and relevant recommendations and considerations for the Legislature. The Roundtable was composed of 26 parents, agency leaders, and professionals with experience and knowledge of the I/DD Waiver process. Each Roundtable member provided a brief introduction. Committee members directed the Roundtable members to identify issues all could agree on and bring those to the Committee while continuing to work on issues where agreement was lacking, help the Committee stay on track and develop a more flexible waiver, consider transportation issues, and prioritize waitlist reduction.

### ***I/DD Waiver Options and Administrative Processes***

A joint presentation by KDADS and Kansas Department of Health and Environment (KDHE) representatives outlined the history and purposes of the HCBS I/DD Waiver and the waiver approval process.

The KDADS representative noted the points of entry for the I/DD Waiver are the Community Developmental Disability Organizations (CDDOs) designated in each area of the state. The KDADS representative stated there were 4,814 individuals on the I/DD waitlist as of August 2022, with a 10-year wait time for the individual waiting the longest. KDADS was pursuing a waitlist study project using one-time funding through the 10 percent federal medical assistance percentage (FMAP) enhancement to improve data-driven funding decisions by enabling the State and providers to develop data-driven strategic plans that could include a new CSW as an option to reduce the waitlist. Development and implementation considerations for the CSW were provided by the KDADS representative.

The KDHE representative reviewed the HCBS waiver approval process, a joint effort between KDADS and KDHE, which would result in a waiver application being submitted to the federal Centers for Medicare and Medicaid Services (CMS). After the CMS waiver application review and approval, the State could initiate implementation of a new waiver. The representative explained if a new HCBS waiver is considered supplemental to an existing waiver, no transition is required. If a new waiver replaces a

current waiver, a transition process is required. The KDHE representative stated a transition process is onerous. The KDHE representative noted the state agencies were not looking to replace the current I/DD Waiver, but to add a new waiver to serve more individuals and tailor services to meet the needs of those individuals.

The KDHE representative explained the current Kansas Medicaid demonstration waiver allowed by Section 1115 of the Social Security Act (1115 waiver) is an umbrella over all HCBS waivers. If the 1115 waiver were to change, it would not change the HCBS waivers allowed under Section 1915(c) of the Social Security Act (1915(c) waivers). Changing Medicaid from an 1115 demonstration waiver to a waiver under Section 1915(b) of the Social Security Act (§1915(b) waiver) would allow the State to no longer worry about federal spending caps on what the State chooses to do with those waivers.

### ***Presentations on Other States' I/DD Waivers by State Agencies***

Presentations were made by representatives of the following state agencies responsible for the administration of I/DD waiver services: the Missouri Department of Mental Health, the Ohio Department of Developmental Disabilities, the Oklahoma Department of Human Services, the Pennsylvania Department of Human Services, the Tennessee Department of Intellectual and Developmental Disability, and the Washington State Department of Social and Health Services. Written-only information was provided by the Colorado Department of Health Care Policy and Financing and the Wisconsin Department of Health Services.

Presentations by representatives of the other states' agencies included the following information on each state's multiple I/DD waivers: waiver services; application process and functional assessment; funding sources; waitlist status, management, and elimination plans and access to resources while on the waitlist; data collection and analysis to forecast and plan for future needs; self-direction features; studies to improve and track health outcomes; and efforts to address workforce shortage and retention. Additionally, the representatives discussed state initiatives including Employment First, Technology First, Enabling

Technology, and Housing Transition and Sustaining Service.

***Presentations from Other States' Developmental Disability Council Directors and Advocates***

The Committee heard presentations from other states' developmental disability council directors and advocates regarding the success of and need for improvement of the various states' I/DD Waivers from the stakeholders' perspectives. Presentations were made by representatives of the North Carolina Council on Developmental Disabilities, the Pennsylvania Developmental Disabilities Council, the Tennessee Council on Developmental Disabilities, and the Wisconsin Board for People with Developmental Disabilities.

The concerns identified by the developmental disability council directors and advocates included:

- Addressing the fragmentation of services due to a shrinking provider network of highly trained professionals with specialized skills and the expertise necessary to successfully work with specialized populations, which was an unintended consequence of adoption of one HCBS waiver to serve frail elders, those with physical disabilities, and individuals with I/DD;
- The need to build provider capacity;
- Addressing aging unpaid caregivers and caregiver shortages that impinge on available services;
- Addressing prevalence data indicating the state may be serving less than one-tenth of its developmental disability population, and funding for HCBS cannot keep up with the need of the unserved population;
- Meeting the unique needs of individuals on Employment and Community First Choices;
- Reaching individuals needing services who are not connected to the system;

- Providing HCBS information to the public in accessible, understandable, plain language;
- Addressing a waitlist for the unserved and underserved;
- The lack of individualized services in private homes due to workforce shortages; and
- Working with inadequate state budget allocations to eliminate the waitlist and provide the services necessary.

Successes or benefits identified by the developmental disability council directors and advocates included:

- Increased awareness of the number of unpaid and aging caregivers, resulting in more interest in technology and housing and addressing family future planning and transition when appropriate;
- Creation of a new Community Living Waiver to address the waitlist by providing up to \$85,000 per person per year, which fills the gap for those living in private homes whose needs could not be met by a smaller waiver capped at \$41,000 per person annually and not obligating the state to provide the services of the comprehensive I/DD Waiver;
- Implementation of Advanced Supported Employment to the Employment First Services;
- Use of the Prioritization of Urgency of Need for Services (PUNS) tool to collect data and analyze it for greater awareness of the needs of individuals on the waiting list and their families;
- Ensured enrollment in services for high school graduates transitioning from school; and

- Flexibility for individuals to move to a higher waiver as needs change.

The representative of the North Carolina Council on Developmental Disabilities outlined the transformation of its Medicaid system by developing a Tailored Plan for individuals with I/DD that uses Section 1915(i) of the Social Security Act (§1915(i)) to transition a person from an institution to a community setting. The plan uses Community Living and Support services to enable an identified person age three and older to live successfully in their home. The 1915(i) program is not a waiver, but is part of a State Plan and is an entitlement. The services under the 1915(i) program are not available to individuals with the most comprehensive needs who are under the Innovations Waiver, which had 15,585 individuals on the waitlist as of the meeting date.

### **October 13 Meeting**

At its October 13 meeting, the Committee received three documents prepared by KLRD staff in response to Committee requests made at the September 28 meeting: a memorandum containing responses to questions from the prior meeting, a memorandum on assessment tools for individuals with I/DD, and a spreadsheet on waiver support assessments by state.

The focus of the October 13 meeting was a series of Roundtable discussions facilitated by KHI staff. The Roundtable discussions provided the Committee members with an opportunity to hear the Roundtable members' considerations focused on the topics of workforce, the I/DD Waiver waitlist, assessment tools, and services and to ask questions and provide input on the discussion topics. The topics for the Roundtable discussions were developed from a survey distributed to Roundtable members prior to the meeting. KHI staff explained the topics would assist the Committee in formulating recommendations for a new, less comprehensive waiver to address the needs of individuals with I/DD and help reduce the waitlist.

The Kansas Disability Rights Center provided written testimony containing additional feedback on the Roundtable Survey Tool.

### ***Roundtable Discussions***

#### *Workforce*

The Roundtable members' comments on workforce included the following:

- Additional training for caregivers is required to meet the needs of individuals with more complex needs;
- Without a higher rate of reimbursement for caregivers and agencies, recruitment and retention of a trained workforce will fail to meet the needs of the I/DD population;
- Two training programs, the Kansas Registered Apprenticeship Program administered through the Department of Commerce and the Systemic, Therapeutic, Assessment, Resources, and Treatment (START) behavioral training program could assist in covering the cost of training the I/DD workforce and could attract more individuals to the workforce;
- Regarding the I/DD Waiver workforce, it is important to look at the advanced skills requirement, workforce credentialing and regulation for accountability, and employer authority for super-care workers who can provide a variety of direct care tasks;
- Kansas needs supported living for individuals with I/DD who want to remain in a family setting. Kansas has a shared living program in residential supports in the I/DD Waiver that could be adapted;
- A continuum of care is needed to adapt to a person's changing needs. Self-directed care is one way to address the changing needs of an individual;
- There is a need to address aging family caregivers when they can no longer care for their family member with I/DD; and
- Having one department for I/DD services would simplify the I/DD system's



structure and the navigation process for families trying to access services, especially for individuals with complex needs.

### *I/DD Waiver Waitlist*

KHI staff referenced the comments included in the Roundtable member survey related to the I/DD Waiver waitlist and invited members to comment on the subcategories of targeted case management (TCM) and assistance in the navigation of services. Roundtable members made preliminary observations that a multi-pronged, multi-year approach that includes early intervention would best serve I/DD families.

**Navigation.** The Roundtable members' discussion on navigation focused on the following points:

- A one-stop system for the assessment questionnaires is needed, with the same intake forms used for all CDDOs;
- The waitlist process needs to be more transparent for caregivers. Increased transparency would also give providers the ability to forecast needs;
- Navigators would fill a gap in communication among the various entities. Roundtable members suggested a university or the CDDOs would best serve as navigators. A targeted case manager enters the waiver process too late to serve as a navigator;
- The Charting the LifeCourse framework is a problem-solving tool and an excellent resource for navigation; and
- The Tennessee approach to navigation offers a model to consider.

**TCM.** The Roundtable members made the following comments:

- TCM services are provided through the Medicaid State Plan. Individuals on the I/DD Waiver receive TCM. Medicaid

eligible individuals on the I/DD waitlist have access to care coordination through the MCO and TCM through the CDDO. Due to a shortage of targeted case managers, some individuals are on a waiting list for TCM; in those cases; the MCO is expected to provide additional assistance;

- I/DD TCM services are paid at an hourly rate of \$43.32, which has not been adjusted for a decade and only covers about half of the cost of providing TCM. A rate of \$75 per hour would bring TCM to a level of sustainability; and
- Targeted case managers are limited in the assistance they can provide. Well-trained navigators are needed and can provide additional assistance to locate community resources beyond what TCM provides. A roundtable member noted the navigator services need to be at the state level to ensure they have the newest and most accurate information and to avoid misinformation.

### *Assessment Tools*

The Roundtable members discussed the following assessment tool considerations:

- Some rules for assessment are from CMS. BASIS is one assessment tool adopted for those rules, which is a deficit-based tool with excessive costs; the SIS offers a more positive assessment that is less intrusive and focuses on a person's strengths. In light of these statements, Committee members asked for the cost of the BASIS assessment, the cost to administer it, why Kansas uses the BASIS, the length of time needed to switch to SIS, and the cost and steps involved in the switch;
- Standardized assessment guidelines are needed for the CDDOs. Inter-rater reliability is needed across all CDDOs;
- The Medical Functional Eligibility Instrument (MFEI) is similar to interRAI;

- The Priority of Need (PON) assessment could help determine access to services; and
- Some members believed an annual contact with the CDDO would help evaluate changes in need for those on the waitlist.

### *Services*

Roundtable members discussed specific service areas to be included in an I/DD waiver and provided comments on the prioritization of themes of services, including CSWs, transportation, self-direction and individual budget authority, resources for individuals with complex needs, supported employment, enabling technology and remote supports, family supports, safe and affordable housing, children’s waiver services, and students transitioning out of school services into adult services.

**CSW.** Roundtable members focused the majority of comments around a CSW, which would be available to those who do not need 24-hour comprehensive care. Roundtable member comments included:

- Many CSWs have cost caps, which if exceeded would move the person to the next applicable waiver with a higher level of service;
- The Autism Waiver has few benefits and could be expanded to cover populations of all ages and be merged into a CSW;
- Respite services should be included;
- The resources of all stakeholders should be utilized in designing a CSW so the scope does not create service gaps; and
- Inter-rater reliability should be completed to ensure the assessments are rated in the same manner by all CDDOs.

**Transportation.** Roundtable member comments included:

- For those with Medicaid services under KanCare, the MCOs provide transportation for clients, and some Roundtable members expressed challenges accessing such services for family members;
- An annual cap could be considered for transportation under a CSW. If transportation is only used for supported employment, it might be possible to cover all transportation for that purpose. To better assess an annual cap on transportation, a data request was made to the MCOs for the average monthly spending for transportation and the number of members using less than the monthly average in transportation;
- If transportation is provided in a proposed waiver, tools must be developed to make the service equitable. Transportation options must be flexible, especially in rural areas where access to transportation may be difficult;
- Two innovative programs in Kansas offer transportation: a Johnson County pilot program using those with mental health issues as drivers to transport individuals with I/DD, and public transportation services serving multi-county areas developed in north-central and northwest Kansas; and
- CDDOs could be a resource in developing transportation services.

**Self-direction and individual budget authority.** The Roundtable members discussed how self-direction and individual budget authority work, how they differ, and how the budget is determined. Individual budget authority allows the family caregivers and the individual the ability to spend the budgeted funds on a set list of items to meet the individual’s needs. Under self-direction in Kansas, with limited exceptions, individuals or family caregivers have employer budget authority that allows them to hire, train, and fire the direct service worker but not individual budget authority. As of 2020, approximately 75 percent of self-

directed programs in the United States have individual budget authority. The Roundtable members made the following comments:

- Most states use the interRAI assessment connected with financial management services (FMS) to set up budgets for independent budget authority. The MFEI includes a resource intensity scale that helps with determining the budget. Kansas already has FMS, which could be expanded to set budgets for individual budget authority. FMS providers would need training on assistive technology; and
- A Medicaid buy-in program, the Work Opportunities Rewarding Kansans (WORK) program under Working Healthy, offers individual budget authority. Kansas does not allow members to set their own rates. Although individuals could pay a higher rate, the budget is based on the Medicaid rate for the number of hours of the individual's determined need. A CMS rule applies to the WORK program that requires the state agency to make reasonable attempts to prevent the premature depletion of the funds over which there is individual budget authority. It is uncertain if this same rule would apply to a §1915(c) HCBS waiver program.

**Resources for individuals with complex needs.** Roundtable members discussed resources for individuals with complex needs that could be considered for a CSW. Individuals with I/DD and mental health needs, those with I/DD and Alzheimer's or dementia, and those with profound I/DD and physical health needs are all subsets of the complex needs population. Individuals with complex needs are often beyond the expertise of community support services. A gap in services exists for the complex needs population between community living and state hospitals or intermediate care facilities. Crisis services for this population are also limited.

The Roundtable members commented the CSW was not envisioned as providing behavioral health supports, other than perhaps respite services. If behavioral health was placed into a

CSW, those services would have to be removed from personal care or state plans.

**Supported employment.** The Roundtable discussion on supported employment under a CSW also considered innovations, such as Employment First, enabling technology and remote supports, and Technology First. Roundtable members stressed the need to include the private sector as a resource in supported employment.

Roundtable members stated the current rate of \$12 per hour for supported employment services is inadequate and attracts few service providers, as the job coach typically earns less than the individual they are coaching. It was stated that the rate should be \$48, which is approximately the national average. It was suggested the more competitive and integrated the job is, the higher the reimbursement should be. Additionally, periodic support is needed to maintain the employment. Research by Project Search indicates that individuals with I/DD who receive support for their work experience maintain a 70 percent retention rate while retention falls to 0 percent within five years for those without support.

A Committee member provided information regarding Washburn Institute of Technology's (Washburn Tech's) pilot program for technical education for students with Individualized Education Programs (IEPs) that is available to all high schools served by Washburn Tech. The Kansas State Department of Education and Washburn Tech will work to identify the potential skills of students with IEPs and how they may fit into the certificate programs and technical career pathways at Washburn Tech. Washburn Tech would build in counseling and supports for these students. As of the meeting date, funding allocated by the Legislature had not been received by Washburn Tech or the high schools, but a counselor had been hired to work with high school and college students with I/DD who have IEPs.

A Roundtable member shared information on Project Search, a supported employment program with 15 sites that creates a bridge from education to employment.

**Enabling technology and remote supports.** Roundtable members stated Technology First and

Employment First offer resources for assistive technology. Technology First is a statewide initiative in Oklahoma that considers enabling technology as a first option for waiver recipients. It was stated that an array of services in a CSW should include technology resources, which must be offered but not required.

**Family supports.** The Roundtable members stated respite services should be included in family supports. It was noted parent support in navigating the I/DD system and training to assist parents to meet the needs of their family member should also be included as a CSW service.

**Safe and affordable housing.** Roundtable members expressed that the removal of barriers for those wanting housing must be a priority. Independent budget authority for individuals with I/DD would allow greater flexibility in wraparound services to make independent living possible. It was noted CMS rules prohibit the use of HCBS funds for room and board.

**Children's waiver and transitioning.** In discussions on the possibility of a children's waiver or services focused on children being included in a CSW, the Roundtable members noted children on Medicaid also have access to a variety of services. The Roundtable members discussed several options to serve children with I/DD through Medicaid. One option was for Kansas, by policy, to allow access to Medicaid through a children's waiver and limit the waiver to a certain disability; this option would disregard parental income. The second option would be implementing the Katie Beckett option to provide Medicaid to all children and youth with a disability under 21 years of age, which 25 other states have done.

[*Note:* The Katie Beckett Medicaid Program established in federal law permits the State to ignore family income for certain children who are disabled and who live at home.]

It was noted that approximately 30 percent of children on the I/DD Waiver do not qualify for Medicaid, likely because of parental income. If parental income was disregarded for children on the I/DD Waiver, these children may not need much funding for HCBS services and could instead access many services through Medicaid

under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) in schools that were not available to them without Medicaid.

The Roundtable members also discussed merging the Autism Waiver into the CSW. It was noted the average age for an autism diagnosis is six and a half years of age. Due to the cost of tests to diagnose autism, many children are not diagnosed until after they are no longer eligible for the Autism Waiver.

### ***Working Group Options***

At the conclusion of the Roundtable discussion, Committee members discussed working group options. The Committee approved one working group consisting of Committee and Roundtable members be formed to address assessment and services in the CSW, with the workforce and waitlist topics to be part of that discussion. KHI staff will facilitate the working group. Participation in the working group is voluntary.

The Committee and Roundtable members noted what they believed to be the key issues: prioritizing the CSW given the limited time available for the working group and Committee to meet; postponing the complex issue of the workforce shortage; focusing on assessment and services and providing solutions, not merely pointing out roadblocks; including training as part of assessment and services; and addressing the need for a new assessment tool.

In preparation for the working group meetings, the Committee members provided directions to the working group regarding items to consider and information to provide to the Committee regarding the assessment tools.

### ***Update on I/DD Waitlist Study***

At the October 13 meeting, KDADS and KDHE staff provided an update on the I/DD waitlist study. KDADS staff reported the I/DD Waiver had 9,039 enrolled, with 4,814 on the waitlist as of August 2022. KDADS has limited information about each individual on the waitlist and has no process to gather information on the current needs or anticipated needs during the next five years of the individuals on the waitlist. Additionally, KDADS staff noted a significant

number of individuals had moved off the I/DD waitlist due to a crisis, and waitlist member information is critical to planning and building system capacity.

KDADS staff stated a planned waitlist study to be conducted by KUCDD will be funded by a 10 percent FMAP enhancement and will cost slightly less than \$1 million, with funds available through March 2025. Committee members stressed the time-sensitive nature of the study and urged completion as soon as possible. KDADS staff noted the spend-by-date was extended to March 2025 to allow for projects that could arise from the study. A copy of the waitlist study contract was provided at the November 1 meeting.

A KUCDD representative reviewed the planned waitlist study, noting the study's partners: the University of Kansas School of Social Welfare Center for Research on Aging and Disability Options, the University of Kansas Institute for Health and Disability Policy Studies, and KDADS. The KUCDD representative explained the aims of the study: to collect and analyze existing waitlist data, interview those on the waitlist, and offer recommendations for reducing the waitlist, which could include more ready access to data systems. The first year of the study will develop a predictive model for risks and services needs, and the second year will offer a comprehensive basis for using the information effectively.

The Committee and Roundtable members provided comments regarding the need to offer preventive care to meet an individual's needs before a crisis occurs, access to services using the Katie Beckett option, and replacement of the BASIS assessment tool with the SIS assessment. The Committee requested it would like to see the progress of the waitlist study survey and weigh in on the questions to be asked.

### ***Additional Resources***

After the October 13 meeting, Roundtable members and KLRD staff provided additional information regarding assessment tools, the CSW decision matrix, services provided by the MCO Aetna, and a list of disability acronyms.

## **Roundtable/Working Group**

The members of the Roundtable participating in the working group met on October 17 and October 21, 2022, with facilitation provided by KHI staff, to review and discuss the elements of the CSW for consideration by the Committee. The Roundtable members completed a short survey between working group meetings relating to the topics of services, individual budget authority, assessments, and cost caps.

## **November 1 Meeting**

At the November 1 Committee meeting, KLRD staff provided follow-up information requested at prior meetings as follows: a memorandum compiling responses to requests from the two prior Committee meetings, a state-by-state chart outlining the funding limits for transportation services for HCBS I/DD waivers, a memorandum on the role of Navigators as health care facilitators as outlined by CMS and different navigator types and programs, a copy of the waitlist study contract awarded by KDADS to the University of Kansas Center for Research, Inc., and an outline of the CDDO eligibility determination process provided by InterHab.

## ***Process for Amending or Creating an HCBS Waiver***

KDHE and KDADS staff reviewed the process for submitting a waiver request to CMS.

Noting the CMS manual for the process is more than 300 pages long, KDHE staff highlighted the salient features of the process for new, renewal, and amended waiver applications. CMS' receipt of an application starts a 90-day clock (using calendar days), during which CMS must approve the application, deny it, or issue a written request for additional information (RAI). An RAI pauses the 90-day clock until CMS receives the requested updated information. Once a state responds to the RAI, a new 90-day clock begins. To avoid a denial of the application if significant problems are identified, a state may also stop the clock by notifying CMS its application is incomplete; when the completed application is resubmitted, a new 90-day clock begins. According to KDHE staff, an application for a new waiver will take at least six months and likely longer, and an RAI should be expected.

Additionally, KDHE staff explained Kansas has been operating the HCBS 1915(c) waivers under a 1115 demonstration waiver, with services administered through the MCOs. Since a 1115 waiver has strict neutrality spending caps, placing a new 1915(c) waiver under a 1115 waiver would impact budget neutrality. The State would prefer to move from an 1115 waiver to a 1915(b) waiver, which has no budget neutrality requirements, which increases spending flexibility. KDHE staff noted, under federal law, application and management of Medicaid waivers are directed by the single state agencies that oversee Medicaid in each state. In Kansas, the single state Medicaid agency is KDHE.

KDADS staff reviewed the details involved in the waiver renewal process: engaging stakeholders; analyzing the fiscal and programmatic impacts of the stakeholder feedback received; writing the impacts into the waiver; review of the waiver by KDHE; opening the public comment period on the waiver; responding to each comment, regardless of whether a change was made because of the comment; making any necessary edits to the waiver after review of the comments; another review by KDHE; and then KDHE submitting the waiver to CMS to start the 90-day clock. The KDADS staff explained the current I/DD Waiver renewal application timeline, which would begin in January 2023 and conclude by July 2024, allotting 180 days for CMS approval after submission of the renewal application. The delay in CMS application approvals was explained by KDADS, as reported by CMS, to be a result of a 300 percent increase in CMS' workload since the COVID-19 pandemic began but with the same number of staff.

Additionally, KDADS staff stated all seven Kansas HCBS waivers are in the renewal or amendment process. CMS will not allow amendments to a waiver when it is in the renewal or amendment process, so the State would have to write an additional eighth waiver for Community Supports, which would be time and labor intensive.

Members discussed the option of creating a CSW and renewing the present comprehensive I/DD Waiver and whether to incorporate the Autism Waiver into either. Concerns were expressed that not all providers would meet the

requirements of the HCBS final settings rule [42 CFR 441.301(c)(4)-(5)], regarding where services are provided, by March 17, 2023, and would need additional time to complete the transition plan, which is an option under an existing waiver. Under a new waiver, all providers would have to meet the settings rule at the time of implementation.

KDADS staff responded to the members' concerns indicating it is on target for approval of its final settings transition plan by March 17, 2023, and the plan involves ongoing monitoring to ensure providers are in compliance with the final settings rule.

KDADS staff noted the State would be better off financially and have more flexibility for those served on the waiver if it keeps the comprehensive I/DD Waiver and creates a new CSW.

### ***Presentation of Roundtable/Working Group Considerations***

KHI staff provided testimony compiling the results of the Roundtable member survey and October 17 and 21 Roundtable/Working Group meeting discussions for consideration by the Committee, which included input from the CDDOs, targeted case managers, and MCOs. The testimony included high-level considerations and recommendations for many components of a CSW. Services to be considered for inclusion in the CSW were provided in the testimony, including their definitions and limitations, definition examples in Appendix A of the KHI testimony, and additional examples of Enabling Support services available in Missouri.

Questions for discussion by the Roundtable/Working Group regarding the CSW included administration roles; eligibility criteria; the special income group/217 group; a waiver cost cap; assessment tools; service plan development; self-direction; quality improvement strategy and metrics; and services.

### ***Committee and Roundtable/Working Group Members' Discussion of Considerations***

The Chairperson explained the purpose of the Committee and Working Group member discussions was to help the legislative members identify services to be included in any proposed CSW for the I/DD population.

### *BASIS Assessment Tool*

Comments expressed by the Committee and Roundtable/Working Group members regarding the BASIS assessment tool included:

- The BASIS tool is intrusive and negative, and the annual requirement for assessment could be accomplished with a condensed assessment in many situations. BASIS is used to determine the tier level of need and the funding required to meet those needs; and
- Research is needed to determine the most effective assessment tool. No other state uses the BASIS, and the SIS is used by 39 other states. Other assessment tools are the MFEI and a similar tool, the interRAI. Moving to another assessment tool will require significant additional funding, with the costs presenting a barrier for such a change.

Committee members agreed to reject the BASIS, but there was no consensus on a replacement assessment tool.

### *Services*

KHI staff reviewed the different kinds of services discussed by the Roundtable/Working Group that could be made available through the proposed CSW. The services included transportation, supported employment, individual directed goods and services, personal care (including personal assistant and personal attendant), respite, therapy, assistive technology, independent living and community engagement skills, family and caregiver support and training, financial management services, support broker, and benefits counseling; and other services including home and vehicle modification, behavioral support, STEPS and community service coordinators, and WORK services, which include supported employment and independent living counseling.

A list of questions not discussed by the Working Group but that should be considered for the CSW application was included in the testimony compiled by KHI staff.

The Chairperson asked for questions from Committee and Roundtable/Working Group members. This led to a discussion on the range of interpretation for self-directed care versus individual budget authority. The Roundtable/Working Group members urged caution regarding the use of the term “self-determination,” as it has a broader meaning and differs from TARC’s self-determination pilot program in the state. For clarity, it was suggested the term “individual budget authority across all waiver services” be used for the CSW to include combined budget and employer authority across all waiver services. It was noted the TARC self-determination pilot program should be looked at as an example.

In response to a question regarding the meaning of “individual goods and services,” a Roundtable/Working Group member noted the definition on page 7 of the testimony compiled by KHI, which defines the term as “a service, support, or good that enhances the individuals’ opportunities to achieve outcomes related to full membership in the community.” The eight criteria each service, support, and good must meet are outlined on the same page.

### ***Committee Discussion and Consideration of Committee Recommendations to the 2023 Kansas Legislature***

KHI staff reviewed the early discussion regarding the CSW and summarized the key points discussed. Committee members were invited to share other priorities that were raised during the discussion.

#### *Autism Waiver Inclusion*

Further discussion and comments centered around the inclusion of the Autism Waiver in the CSW:

- Only an autism diagnosis is needed to be placed on the Autism Waiver proposed recipient list. No functional eligibility assessment is completed for placement on that list. An autism diagnosis qualifies an individual for early intervention services without being on the Autism Waiver;
- As of September 30, 2022, there were 428 individuals on the Autism Waiver

proposed recipient list, with 58 persons eligible to receive services. There is a limit of 65 slots on the Autism Waiver;

- Children aging out of the Autism Waiver who have a dual diagnosis of autism and I/DD and have had a functional eligibility assessment would be eligible for the I/DD Waiver and would be placed on the I/DD Waiver waitlist. Children receiving Autism Waiver services are automatically transitioned to the I/DD Waiver waitlist when they age out of the Autism Waiver;
- Simplifying navigation through the waiver process would enable parents to make more informed choices for their children; and
- Parental income is not considered for individuals receiving waiver services. Parental income is considered for those on the waitlist for I/DD Waiver services, preventing access to non-waiver services such as Medicaid, EPSDT, and case management. Parental income would not be considered for a child to receive services if a parent gave up custody or placed a child in an institution. The Special Income 217 Group exempts parental income to allow eligibility for Medicaid coverage for individuals who would be eligible for Medicaid if they were in a medical institution, would require an institutional level of care in the absence of the provision of HCBS, and will receive 1915(c) services. [Note: This eligibility group is further described in 42 CFR §435.217 and is commonly referred to as the “217 group.”] CMS requires an individual to be on a waiver to get Special Income 217 Group eligibility. If a CSW was created with no waitlist, parental income could be disregarded for those on the waiver, removing the incentive for a parent to give up custody or place their child in an institution. If the CSW lacked sufficient funding, resulting in a waitlist, and a Katie Beckett option was not adopted, parental income would be considered for individuals on that waitlist

and would render some ineligible for Medicaid.

### *Tiered Services and Funding*

The Committee and Roundtable/Working Group members’ discussion moved to tiered services and funding. It was noted a waitlist for the CSW is likely because the cost involved would be approximately \$40 million if the waiver were capped at \$20,000 per person annually and only half of the I/DD waitlist were served. Concerns were expressed regarding inflation and a desire not to have to remove individuals from services if the funding available is reduced. It was noted, if a CSW is created, services would essentially be in tiers, with basic Medicaid, a CSW, and the comprehensive I/DD Waiver.

### *Combining Services, Behavioral Supports, Transitioning, and Funding Caps*

Members noted the range of services considered by the working group and suggested combining vehicle and home modification under home enabling services and placing support broker services under FMS. Noting the growing need for behavioral supports, especially in rural areas, suggestions were made to widen “behavioral supports” to include applied behavioral analysis (ABA) and behavioral supports, broaden the definition of “therapy” to include ABA and positive behavior supports, or expand parent support and training to add behavioral supports.

Members discussed transitioning between the CSW and the comprehensive I/DD Waiver, noting slots could be reserved in the I/DD Waiver. CMS would require the reservation of slots so an individual could return to the more comprehensive waiver to ensure continuity of services if the CSW no longer met his or her needs.

A request was made for KDADS to provide information to the Legislature on the cost of various levels of annual individual caps on the CSW: either aggregated totals for various caps (\$20,000, \$30,000, and \$40,000) or individual caps for each service.

The Chairperson expressed appreciation for the service of the Roundtable members, noting they provided unique perspectives and invaluable



information, and then convened the legislators to offer final recommendations for the Committee's report to the 2023 Legislature.

## CONCLUSIONS AND RECOMMENDATIONS

The Committee generally agreed the State should pursue a CSW. After discussion, the Committee recommends:

- KDADS provide a fiscal impact statement for each service discussed by the Committee for possible inclusion in the CSW;
- A \$20,000 annual individual cap be placed on the CSW;
- The Executive Branch transition the Medicaid managed care system from a 1115 waiver to a 1915(b) waiver;
- KDADS provide an estimate on the number of individuals likely to request self-determination;
- KDHE and KDADS continue to study strengths-based assessments, such as the SIS or the MFEI, as alternatives to the deficit-based BASIS assessment tool for the HCBS I/DD Waiver, with the acknowledgment that the University of Kansas is still working on the financial portion of the MFEI assessment used to determine with funding levels;
- The CSW include individual budget authority across all services; and
- KDHE and KDADS identify a process to prevent children from being removed from the Autism Waiver proposed recipient list without notification.