

# **Report of the Special Committee on Home and Community Based Services Intellectual and Developmental Disability Waiver to the 2022 Kansas Legislature**

**CHAIRPERSON:** Senator Richard Hilderbrand

**VICE-CHAIRPERSON:** Representative Will Carpenter

**OTHER MEMBERS:** Senators Molly Baumgardner, Rick Billinger, Beverly Gossage, and Tom Hawk; and Representatives Barbara Ballard, Brenda Landwehr, Megan Lynn, Susan Ruiz, and Troy Waymaster

## **STUDY TOPIC**

The Committee is directed to review and study issues, including but not limited to, the Home and Community Based Services Intellectual and Developmental Disability waiver waitlist, adequate provider networks, and waiver reimbursement rates.

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# Special Committee on Home and Community Based Services Intellectual and Developmental Disability Waiver

## REPORT

### Conclusions and Recommendations

The Special Committee on Home and Community Based Services Intellectual and Developmental Disability Waiver generally agreed that the State should explore how to move individuals from the Home and Community Based Services (HCBS) Intellectual and Developmental Disability (I/DD) waiver waitlist on to the HCBS I/DD waiver. Therefore, the Committee recommends:

- 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 Legislature approve funding for HCBS I/DD waiver providers to give direct care support workers pay raises as an incentive to retain more long-term employees;
- The Kansas Department for Aging and Disability Services (KDADS) provide recommendations to the House Committee on Social Services Budget and the Senate Committee on Ways and Means Subcommittee on Human Services for increases to the personal care attendant and supportive employment reimbursement rates;
- KDADS conduct an analysis of the targeted case management rates of the HCBS I/DD waiver and compare them to those of the Supports and Training for Employing People Successfully (STEPS) Program and report its findings to the House Committee on Social Services Budget and the Senate Committee on Ways and Means Subcommittee on Human Services;
- The Legislature identify areas in the budget to reduce expenditures in order to provide increased funding for HCBS I/DD waiver expenditures;
- The Legislature study how other states have addressed HCBS waitlists through restructuring those programs under different waiver authorities, and the State's options for its HCBS I/DD waiver;
- KDADS, with the Kansas Department of Health and Environment, collect and provide information on the actual services individuals on the HCBS I/DD waitlist currently need, and separately collect and provide information on the actual services individuals on the HCBS I/DD waiver currently use;
- The Legislature consider providing individual budget authority to HCBS I/DD waiver participants who self-direct their services;

- KDADS evaluate whether projects, particularly state infrastructure and consultant services, identified in its HCBS temporary 10.0 percent federal medical assistance percentage (FMAP) plan may be funded with pandemic-related American Rescue Plan Act (ARPA) funding. If projects may be funded with ARPA funding, then the Committee recommends the agency submit its plans to the Health and Education Advisory Committee of the Strengthening People and Revitalizing Kansas (SPARK) Task Force for consideration; and
- The Legislature explore potential legislation to provide automatic annual adjustments for the HCBS I/DD waiver reimbursement rates. Should the LCC approve an I/DD waiver task force or committee, such committee should explore potential legislation.

***Proposed Legislation:*** None

## **BACKGROUND**

During the 2021 Session, the House Committee on Social Services Budget and the House Committee on Appropriations recommended the Legislative Coordinating Council (LCC) form a special interim committee to review and study issues regarding the Home and Community Based Services (HCBS) Intellectual and Developmental Disability (I/DD) waiver waitlist, including adequate provider networks and I/DD waiver reimbursement rates.

The Special Committee on HCBS I/DD (Committee) was granted two meeting days by the LCC and met October 21 and 22, 2021, at the Statehouse.

## **COMMITTEE ACTIVITIES**

The Committee’s two-day meeting focused on information on the waitlist, workforce issues, and funding and reimbursement rates and on Committee discussion and recommendations.

The Committee received background information on the HCBS I/DD waiver and its waitlist from Kansas Legislative Research (KLRD) staff. The Committee heard testimony from representatives of the Kansas Department for Aging and Disability Services (KDADS) and the Kansas Department of Health and Environment (KDHE) on various issues surrounding the I/DD waiver. Additionally, representatives of various organizations testified concerning other states’

efforts in addressing similar waitlists and provided suggestions to the Committee. Several individuals presented testimony regarding their experience on the waitlist, and several providers testified to their issues retaining qualified staff. The Committee concluded its meeting with a discussion of the various issues and concerns it heard and determined its recommendations to the 2022 Legislature. The key issues and concerns are described as follows.

### **Historical Information and Eligibility Criteria for the HCBS I/DD Waiver**

#### ***Historical Information***

KLRD staff provided an overview of services provided to individuals with I/DD in the state. This overview included information on treatment provided by the state hospitals for individuals with I/DD and the push for “deinstitutionalization” in the 1970s and 1980s. Staff explained how this shift eventually led to the development of HCBS waivers in Kansas. Staff also provided a chart detailing the number of individuals on the I/DD waiver waitlist from September 2012 to September 2021.

#### ***General HCBS Eligibility Criteria***

A representative of KDHE provided an overview of the Medicaid eligibility process and discussed how HCBS factors in financial eligibility as well as functional eligibility. The KDHE representative provided specific information on the resource limits and income standards for HCBS participants. The presentation included several examples of how client obligation

would be calculated depending on a potential participant's income.

A representative of KDADS provided a brief overview of the HCBS I/DD waiver. She explained that costs for HCBS waiver services must remain less than the cost of receiving services in an institution, and that the services provided should follow an individualized, person-centered plan of care. Additionally, she explained the functional eligibility portion of HCBS waiver eligibility. The representative described the following broad criteria an individual must meet for eligibility:

- Be 5 years of age or older;
- Either have been diagnosed by a licensed health care professional with an intellectual disability prior to the age of 18 or a developmental disability prior to the age of 22;
- Be determined program eligible by a community developmental disability organization (CDDO);
- Meet the Medicaid long-term care threshold; and
- Be found financially eligible for Medicaid.

After outlining the broad criteria of HCBS eligibility, the representative described the role CDDOs play in eligibility and outlined CDDOs' responsibilities as required by the State's Developmental Disabilities Reform Act (KSA 39-1801 *et seq.*). Included in the CDDO discussion was a map of the catchment areas of each of the State's 27 CDDOs.

In response to Committee member questions, the KDADS representative clarified that the individual must have received a diagnosis of intellectual or developmental disability before the age of 18 for intellectual disabilities and before the age of 22 for developmental disabilities, but that individual may apply for services at a later date. The representative stated that, due to the waitlist, the agency does not see individuals moving to Kansas from other states as a significant

contribution to the long wait individuals face on the waitlist.

## **HCBS I/DD Waiver Waitlist**

### ***Kansas Department for Aging and Disability Services***

The KDADS representative stated 9,107 individuals are enrolled on the I/DD waiver, with a waitlist of 4,563 as of August 2021. She noted the longest an individual has been waiting was 9.5 years, and that approximately 70.0 percent of individuals on the waitlist also receive Medicaid services through KanCare.

She provided demographic information on those on the I/DD waiver and those on the waitlist, noting that a majority of people on the waitlist are younger than 35, with 39.0 percent between the ages of 13 and 21, and a large portion of individuals on the waiver and waitlist are male.

In her overview of the waitlist, the KDADS representative explained how individuals can begin to receive waiver services via a crisis or various exception requests. With respect to crisis requests, she indicated there must be either:

- Documentation from law enforcement or the Department for Children and Families (DCF) supporting the need to protect the individual from confirmed abuse, neglect, or exploitation; or
- Documentation substantiating that the individual is capable of and at significant, imminent risk of performing serious harm to themselves or others.

The KDADS representative explained additional waitlist expectations apply to crisis requests, which largely center around individuals transferring from institutions or DCF custody back to the community. The KDADS representative stated approximately 50 individuals make that transition each quarter, which translates to approximately 200 to 250 individuals a year.

The KDADS' waitlist presentation included information on Louisiana's efforts to address its waitlist and Kansas' plan for a waitlist study.

The KDADS representative highlighted how Louisiana utilizes a screening tool to determine an individual's need for waiver services. Individuals who are determined to need support within a year are prioritized for services appropriate to their needs. Other individuals are placed on a registry to be reassessed periodically at certain times.

She also highlighted how a portion of Louisiana's efforts are the result of having a different waiver structure than that of Kansas. Kansas utilizes a comprehensive waiver structure, under which an individual on the waiver is entitled to all services offered through the I/DD waiver. Louisiana's waiver includes five separate programs for I/DD services, which allows the state to provide participants tailored services to meet their needs.

The KDADS' representative provided an overview of the State's plan to study the I/DD waiver waitlist and determine how it can identify and monitor the needs of individuals on the waitlist. To fund this study, the agency plans to utilize moneys from a temporary 10.0 percent increase in the federal medical assistance percentage (FMAP) for HCBS waiver services included in the American Rescue Plan Act of 2021 (ARPA).

The Committee's questions focused on how Louisiana addressed its waitlist and included discussion on how Kansas can potentially utilize a different waiver structure to move people off the waitlist. In response to a question, the KDADS representative provided a rough all-funds estimate of \$200.0 million to move everyone from the waitlist onto the waiver; she also indicated the system did not have the capacity to provide services to everyone on the waitlist. Additional questions centered around the demographics of individuals on the waitlist and how the State can identify the current needs of individuals on the I/DD waitlist.

### ***Intellectual/Developmental Disability Organizations***

Various I/DD organizations and advocates provided presentations.

Representatives of InterHab provided an overview of its report and recommendations for

the Committee. The InterHab representatives provided a brief overview of I/DD waiver funding and reviewed a survey the organization conducted through its member CDDOs in an effort to provide some demographic information for the Committee. They described some of the efforts made by other states in addressing similar waitlists, primarily utilizing different waiver authorities to allow individuals to receive select services, as opposed to the comprehensive structure Kansas utilizes. They suggested recommendations for the Committee, which centered around funding and alternative waiver authorities in federal law.

A representative of the Kansas Council on Developmental Disabilities discussed the elimination of the I/DD underserved list in 2014 and expressed a need for the State to have a strategic plan to study the waitlist. He noted that individuals on the waiver and waitlist total approximately 13,000 individuals, and that approximately an additional 43,000 individuals in Kansas have an intellectual or developmental disability. He highlighted some of the supports individuals and families have indicated they need. The representative also spoke about the Supports and Training for Employing People Successfully (STEPS) pilot program at KDHE, which aims to assist individuals with employment and independent living supports. He requested funding the I/DD waiver and building system capacity.

A representative of the Disability Rights Center of Kansas provided testimony regarding the I/DD waitlist. He also requested an in-depth study of the waitlist. He elaborated that any study conducted should be followed up with a task force to develop recommendations to address the I/DD waitlist. He noted that the process in Louisiana to develop the state's plan included a task force that included legislators, agency staff, self advocates, families, providers, and other experts. He also noted several other efforts to assist individuals on the waitlist in Kansas, including supportive decision-making, school-to-community transitions through the Kansas Department of Education, and the STEPS pilot program at KDHE.

A representative of the Self Advocate Coalition of Kansas provided a view of the waiting list from an individual who was once on the list. He testified that he considers the services he received through the waiver as being one of the

reasons for his independence and employment. He also expressed concern over the nine-year wait for waiver services and how that wait might affect an individual with I/DD graduating from high school without waiver services.

A representative of the Kansas University Center on Developmental Disabilities testified regarding the Center's work in assisting individuals with disabilities through training, technical assistance, research, and information sharing. He reviewed several issues regarding the I/DD waiver including the waitlist: the use of the crisis exception as an entry point to the waiver, inconsistency in where services are offered in the state, and low employment rates for individuals with I/DD. He highlighted that the length of time on the waitlist creates instances in which individuals leave high school without continuation of services they had maintained through the school system.

The Kansas University Center on Developmental Disabilities representative provided information in discussion regarding the outcomes of federal grant-funded studies and Center efforts to assist individuals with I/DD transition from high school into the community, unnecessary guardianship, and educating parents on other services, such as supportive decision making, to help avoid guardianship.

### ***Individuals on the Waitlist***

The Committee heard testimony from several parents with children on the I/DD waitlist. Several individuals indicated that they had applied for services within the past year and half and are expected to wait approximately eight to ten years for services. Another individual stated her child had been on the waitlist for approximately five years, and she anticipates waiting another six years for services.

The testimony offered by individuals centered around the issues they experienced finding services for their children outside of the HCBS I/DD waiver. Additional discussion topics included income limits for someone with intellectual or development disability to receive Supplemental Security Income, services provided through schools, and how school-based services interact with the HCBS waiver services.

## **Adequacy of HCBS I/DD Waiver Services Provider Network**

### ***Kansas Department for Aging and Disability Services***

A representative of KDADS provided a brief presentation regarding issues surrounding the I/DD provider workforce that included an overview of the national demand for direct care support workers, while highlighting that the national average hourly wage for the direct care workforce is approximately \$13.50 with average annual earnings of \$28,000.

She provided Kansas-specific statistics indicating that Kansas is ranked 42nd in the nation in the direct services worker average hourly rate (\$11.30) and annual salary (\$23,520). She also indicated that, on average, each \$1.00 increase in the hourly rate decreased the caregiver turnover by 3.0 percent.

The KDADS representative provided an overview of how the agency anticipates to utilize moneys from the temporary 10.0 percent FMAP increase to assist the workforce. The agency's current plan for the workforce includes:

- A recruitment and retention bonus program to attempt to increase retention rates throughout the state;
- Providing training grants to improve the quality of care, opportunities for professional development, and direct support worker retention rates; and
- Studying and designing a career ladder to incentivize longevity and promotion opportunities while increasing workers' earning potential in an effort to decrease turnover.

In response to Committee questions and comments on support for providing funds directly to the direct care workforce and use of FMAP moneys, the KDADS representative said these projects were envisioned as an effort to help stabilize the system while the agency explored long-term solutions.

## ***Direct Care Support Workers and Provider Organizations***

The Committee heard several accounts from representatives of HCBS I/DD waiver service providers Aetna Better Health of Kansas, Big Lakes Developmental Center, COF Training Services Inc., Sunflower Health Plan, Starkey Inc., and Tri-Ko Inc. about experiences with workforce challenges. Several provider organization representatives expressed concern over the competition their organizations face with similar fields such as nursing care where employees might leave to provide care at a nursing facility to receive a higher hourly rate. Provider representatives detailed how their employees must cover multiple shifts as they experience staff shortages.

The representative from Big Lakes Developmental Center thanked the Legislature for the reimbursement rate increase provided in 2021, as it helped increase the hourly rate for direct care workers, but expressed concern over the wage competition with similar industries. The representative further explained that it was difficult to provide residential services for an individual given the 24/7 nature of the services and the low reimbursement rate the provider receives.

A direct care support worker from Big Lakes Developmental Center explained that the high turnover creates a continuity of care issue, where waiver participants lack a consistent individual providing services. She expressed concern that staffing shortages may lead to errors in medication and accidents for both participants and staff, as well as staff exhaustion.

A representative of Sunflower Health Plan (Sunflower), a KanCare managed care organization (MCO), testified that while Sunflower has not experienced a shortage in providers willing to provide services, it has seen an increase in providers not taking on new clients. She indicated Sunflower is exploring how the use of technology, such as smart home technology that can provide remote medication assistance, can be used to help alleviate workforce issues.

Additionally, she stated Sunflower had been looking into how the COVID-19 family caregiver

exceptions can be extended to allow for a flexible subsidy to encourage caregivers as providers.

Committee members expressed admiration for the work providers performed, especially during the pandemic. In response to questions, conferees provided information on how providers are paid, including how the reimbursement rates translate into a direct care support worker's hourly rate. The representative of Big Lakes Developmental Center indicated that organization tries to estimate what it will receive in reimbursement rates and then calculate what it can provide staff based on the average need of clients. In response to a question, a KDADS representative said there are approximately 300 I/DD waiver service providers in Kansas.

## **Funding for the HCBS I/DD Waiver and Provider Reimbursement Rates**

The Committee began its review of funding and reimbursement rates with a presentation from KLRD on the historical funding for the I/DD waiver.

### ***Budget Neutrality***

The State Medicaid Director, KDHE, provided information on Medicaid budget neutrality and how that affects the State's ability to provide increases for Medicaid-related expenditures. She provided a brief history of the KanCare programs. She explained that KanCare is implemented under a federal 1115 waiver of certain requirements of the Medicaid program, which requires that the state Medicaid program not cost more than it would absent the 1115 waiver. [*Note: Section 1115 of the Social Security Act gives the U.S. Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration programs the Secretary finds to be likely to assist in promoting the objectives of the Medicaid program.*]

She indicated the budget neutrality cap remains in effect throughout the waiver's life, and that Kansas would be responsible for any costs above the cap. She noted that, with every change to the KanCare program, the State should be cognizant on how the change will impact the 1115 waiver budget neutrality cap.



She indicated that in 2019, the State appeared to have a \$1.0 billion budget neutrality cushion, and projected to end the waiver period, in December 2023, roughly \$568.0 million below the budget neutrality cap. She said that subsequently, the federal Centers for Medicare and Medicaid Services (CMS) made accounting errors that reduced Kansas' cap. She stated KDHE was in the process of submitting a proposal to CMS to correct those errors, but until CMS approves those changes, the State will not have as much budget neutrality room as it originally anticipated.

### ***Use of Federal and State Funds***

A representative of KDADS provided a brief overview of the how HCBS waivers are funded with a mix of state and federal funds. She explained the federal share is calculated using FMAP. Absent the 10.0 percent FMAP increase as a result of ARPA, the FMAP is approximately 60.0 percent, meaning for every dollar the state spends on HCBS, 60.0 percent of that dollar would be funded with federal moneys and the remaining 40.0 percent would come from with state funds.

The representative explained the KanCare MCOs receive a per-member-per-month payment to provide Medicaid health services and additional HCBS waiver services. For FY 2021, MCO payments were approximately \$4,000 per member per month. She then provided an overview of the reimbursement rates the MCOs use when reimbursing providers for I/DD waiver services.

### ***Funding and Provider Reimbursements***

A representative of the Disability Rights Center of Kansas provided testimony regarding funding for the I/DD waiver. The representative's testimony included detailed recommendations to increase funding for the waiver, including adding funding for the waiver as the system builds capacity, significantly increasing rates for certain one-on-one services, and incorporating a process for ongoing rate adjustments. He reiterated his support for a study on the waiver, including studying the need to adjust reimbursement rates. He additionally recommended the State consider providing individuals who self-direct services individual budget authority to allow them more control in addressing their needs.

A representative of Sunflower provided an overview of its value-based payments system to allow for extraordinary circumstances. She clarified how some providers may receive an increased reimbursement rate when an individual's needs exceed those of an average participant. She also expressed concern over the discrepancy in the specialized nursing care reimbursement rate created when the Legislature increased the rate for the Technology Assisted (TA) waiver code but not for the I/DD waiver. She stated the discrepancy created some issues with providers accepting referrals only for individuals on the TA waiver.

## **CONCLUSIONS AND RECOMMENDATIONS**

The Committee generally agreed the State should explore how to move individuals from the HCBS I/DD waiver waitlist to the waiver. After discussion, the Committee recommends:

- The Legislative Coordinating Council 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 Legislature provide funding for HCBS I/DD waiver providers to give direct care support workers pay raises as an incentive to retain more long-term employees;
- KDADS provide recommendations to the House Committee on Social Services Budget and the Senate Committee on Ways and Means Subcommittee on Human Services for increases to the personal care attendant and supportive employment reimbursement rates.;
- KDADS conduct an analysis of the targeted case management rates of the HCBS I/DD waiver and compare them to those of the STEPS Program and report its findings to the House Committee on Social Services Budget and the Senate Committee on Ways and Means Subcommittee on Human Services;

- The Legislature identify areas in the budget to reduce expenditures in order to provide increased funding for HCBS I/DD waiver expenditures;
- The Legislature study how other states have addressed HCBS waitlists through restructuring those programs under different waiver authorities and the State's options for its HCBS I/DD waiver;
- KDADS and KDHE collect and provide information on the actual services individuals on the HCBS I/DD waitlist currently need, and separately collect and provide information on the actual services individuals on the HCBS I/DD waiver currently use;
- The Legislature consider providing individual budget authority to I/DD waiver participants who self-direct their services;
- KDADS evaluate whether projects, particularly state infrastructure and consultant services, identified in its HCBS temporary 10.0 percent FMAP plan may be funded with pandemic-related ARPA funding. If projects may be funded with ARPA funding, then the Committee recommends the agency submit its plans to the Health and Education advisory committee of the Strengthening People and Revitalizing Kansas (SPARK) Task Force for consideration; and
- The Legislature explore legislation to provide automatic annual adjustments for the HCBS I/DD waiver reimbursement rates. Should the Legislative Coordinating Council approve an I/DD waiver task force or committee, such committee should explore potential legislation.