Bob Bethel Committee on HCBS and KanCare Oversight
Testimony by Kathy Keck- Parent advocate and concerned citizen
October 11, 2023

Good morning, Madame Chairman and Members of the Committee. My name is Kathy Keck. I am a mom of five kids, three with complex medical and developmental disabilities. Thank you for allowing me to continue to come before this committee.

Home and Community Based Services are intended to keep individuals out of the hospital and living in the least restrictive community setting possible. DME and home modifications are not only critical to sustain community living for individuals with complex needs, but also having appropriate equipment also reduces unnecessary and expensive hospital visits.

The bureaucracy and red tape associated with getting a home modification is costing more than the actual modifications with staff time, resource not to mention the extreme stress placed on individuals and families.

Our struggles began in February of 2022. I have outlined our journey below. I am appalled that we are no closer to a resolution today than we were in 2022. Our home modification request is to modify our master bedroom into a space for our daughter that is accessible for her and all of her necessary medical equipment, to modify a bathroom that is accessible to her and create an exterior door so that nurses and therapist can enter directly into her living space and not be exposed to everyone else (6 other house members plus their attendants) germs. These modifications and upfront investments would help increase her independence, quality of life and reduce her risk of infections that led to costly hospital stays.

Our care coordinator is a strong advocate for our family and has tried to help us navigate the system however there is so much red tape and so few providers contracted to do the work that it deters people from pursing this option and impacts the timeliness to receive the help needed. In addition, there is inequity based on the waiver you are on.

I need to make it clear that our family has had a unique experience with KanCare as we work with 2 different MCO's currently Aetna and Sunflower, but also worked with Amerigroup when KanCare began. Our experiences with Amerigroup and Aetna have been nothing but positive. In fact, this past year we needed assistance for my older son Jacob with a vehicle modification and the process from my first conversation with his care coordinator to the installation of the needed equipment was ***less than 2 months****!* That is impressive and should be the standard of practice and not the exception. Our experience with Sunflower has been a nightmare for our family.

When a company is making millions of profits annually, it is imperative to listen to the voices of the end users and utilize data to confirm the realities happening to individuals and families in this state. After all our skin in the game is much more than profit, it's our lives!

Mireya/Sunflower Member Home Modification Request Timeline:

- Initial email sent to care coordinator in February 2022

- In December 2022, I began to inquire again with our new CM about the process.
- In February 2023, I submitted a formal request to our CM Gailyn Ledom regarding a home modification.
- On March 30th, 2023, our CM requested information to move forward with the home modification process.
- On April 25, 2023, ironically after my testimony at Bob Bethel on April 21, 2023, it appeared all the requirements to start the process had changed and Sunflower sent TWO different contractors to give us a bid.
    - On May 10, 2023, one bidder (LifeWise) completed their assessment. They were much more thorough in their assessment and measured all of Mireya's equipment. The following information in their report could be the cause of the confusion as some of the information misrepresents the request. ***LifeWise did make it clear they would only give us a bid for what Sunflower authorizes a bid for.***
    - On May 11, 2023, one bidder spent less than 30 minutes at our house (Thrive) and didn't seem interested in the totality of the request. Nor did they measure all our daughter's necessary medical equipment.
    - On June 12, 2023, Sunflower requested a meeting with us to better understand the totality of the home modification request. We accommodated this request (in between our daughter's multiple hip surgeries) and brought the medical director and others on your team on a virtual walk through of our home and the barriers we are facing. **
    - On July 26, 2023, at 11:43am I reached out to CM expressing concerns about the lack of transparency and not seeing any bids to date.
    - On July 26, 2023, at 4:51pm Stephanie Rasmussen sent over the bids for us to review.
    - On July 27, 2023, at 12:39pm Stephaine Rasmussen sent an email informing us that Sunflower was not going to move forward with the entire home modification regarding the bedroom remodel and that a formal notice of action would be coming.
    - On July 28, 2023, at 6:18pm we received an electronic copy of the notice of action.
    - On July 28, 2023, at 6:27 I sent an email to Sunflower informing them that we wanted to file an appeal on the Notice of Action
    - On July 31, 2023, the leadership team at Sunflower and Lifewise Contractor, Steve, met with me to review the bids. I expressed concerns that the entire request was not considered. Both bids proposed removed a functioning toilet from our household of 7. One of their bids removed a bathtub that is necessary for one of our other children.
    - August 2, 2023, email sent to Stephanie Rasmussen regarding our concerns of the process and discrepancies with the original home modification request.
    - August 8, 2023, informed I could submit additional documentation for the appeal by August 15, 2023
    - August 14, 2023, I asked for an extension to Aug 18 to provide additional information. Request accepted.
    - August 17, 2023, additional information submitted to Sunflower including letter from pediatrician.
    - August 21, 2023, received daughters' records from Sunflowers compliance department that were requested in July 2023.
    - August 22, 2023, receive notification and copy of letter upholding the original denial dated 8.21.23
    - August 25, 2023, sent email to Sunflower and Secretaries of KDHE and KDADS of concerns regarding lack of transparency, misinformation, and process of home modification.
    - August 28-Sept 1, 2023, email exchanges between Sunflower and I. Sunflower requested to meet again to discuss.
    - September 6, 2023, meeting with Kecks, Sunflower and KDADS with no resolution.
    - September 21, 2023, State Fair Hearing Filed.

My Asks Today:

- ***Create a streamlined and simplified process to make access possible for individuals and families in a timely manner- within 90 days -that is the standard across ALL MCO's and waivers.***
- ***Eliminate administrative barriers for providers to complete home modifications.***
- ***Increased oversight and accountability of the MCO's with the state agencies on the process.***
- ***Increase transparency of the process to include Home Modification Data reported quarterly, at minimum, to the State agency and the Bethel Committee upon request, to include: number of requests, number of approved request, reasons for any denials, total $$ spent and the time to complete the requests.***
- ***Eliminate inequity for home modifications for children on the TA waiver and align language to reflect the IDD waiver.***

In a data request from Kansas Legislative Research Department, it indicates that in 2012- prior to KanCare, there were 40 enrolled providers of this service. Fast forward to 2023 and the number has dropped by 75%. This reduction creates monopolies and leaves very little choice for families. The MCO's are responsible for network adequacy but also have rules and policies to follow. Being a systems and data geek, this leads me to the following questions:

- *What factors have led to a 75% reduction of provider enrollment causing the network adequacy issue?*
- *Is the process of enrolling providers prohibitive?*
- *Is the current process to enroll necessary by federal or state mandates or statues?*
- *Can the process be streamlined so families could utilize any qualified contractor without requiring the contractors to become a Medicaid provider.*

I'd also like to point out some other data I received from KLRD is at the end of my testimony. Below are some charts and graphs I created, based on the data from KLRD, to demonstrate the concerns our family is experiencing with Sunflower in addition to the stories I hear over and over from families. If the purpose of Managed Care System is to monitor and control expenditures of taxpayers' dollars then the information I received should be readily available any time it is requested. The red tape discourages individuals and families from even trying to get the much-needed help they need. In Chart # 1 you can see the comparison of dollars spent on assistive services/assistive technology since 2015 by each MCO. Sunflower has spent significantly less than any of the MCO's. This is concerning since Sunflower has the largest % of individuals they serve on waivers- see chart #5. Sunflower has also completed the fewest number of assistive services (home modifications)- see Chart 2- only 241 since 2015. In the month of July Sunflower caseload consisted of nearly 9000 members on a waiver that could potentially be eligible for a home modification. However, only 241 total services have been rendered since 2015. This is unacceptable and validates our experience and the stories I have heard from others. Due to the struggles accessing necessary services, many families switch to a different MCO. Families should not have to change MCO's to have their needs met. Digging deeper into the data helps maintain accountability and address systemic issues.

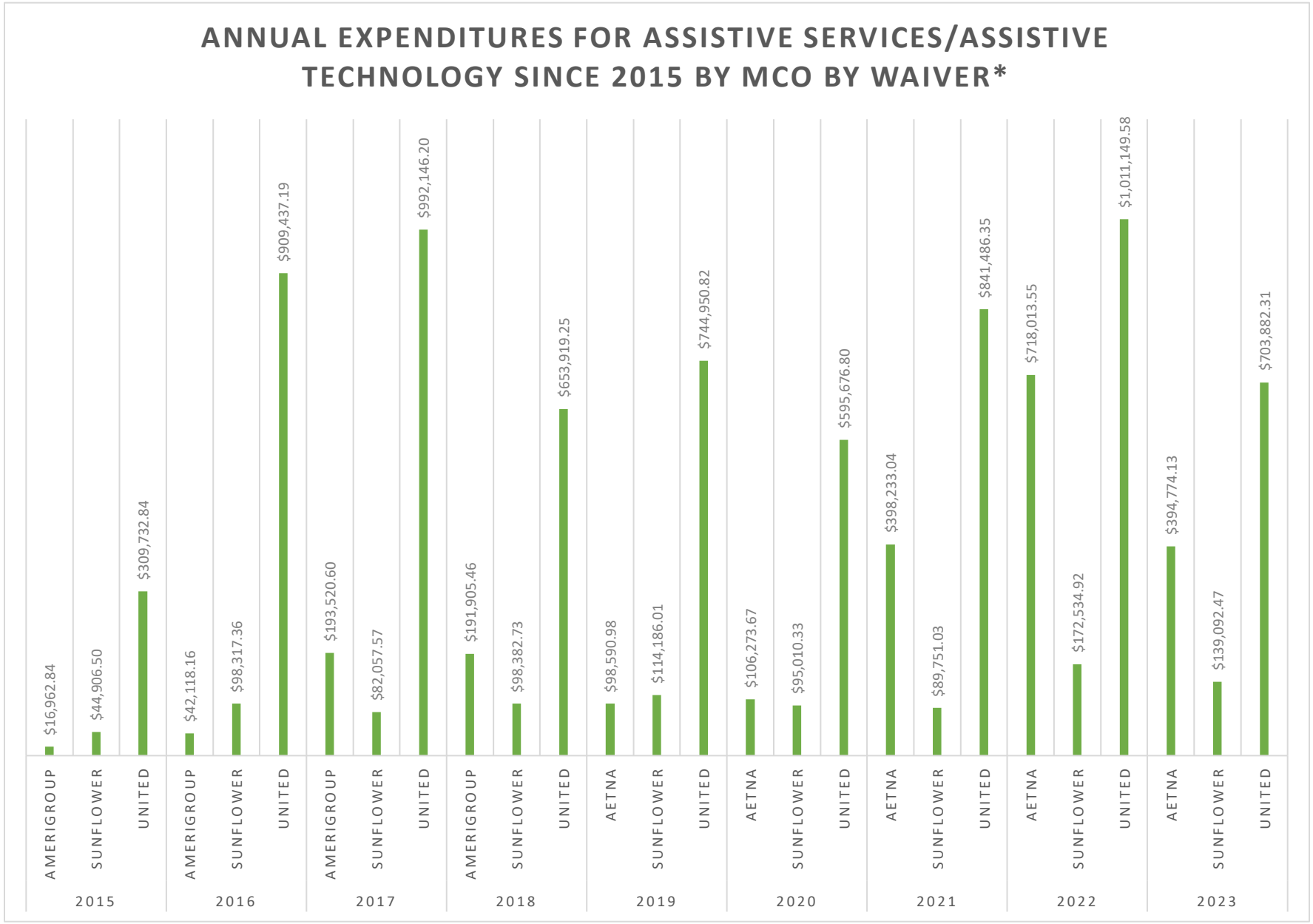
Thank you for your continued time and assistance in addressing the issues that impact the most vulnerable individuals and families in our state.

Kathy Keck

Private Citizen

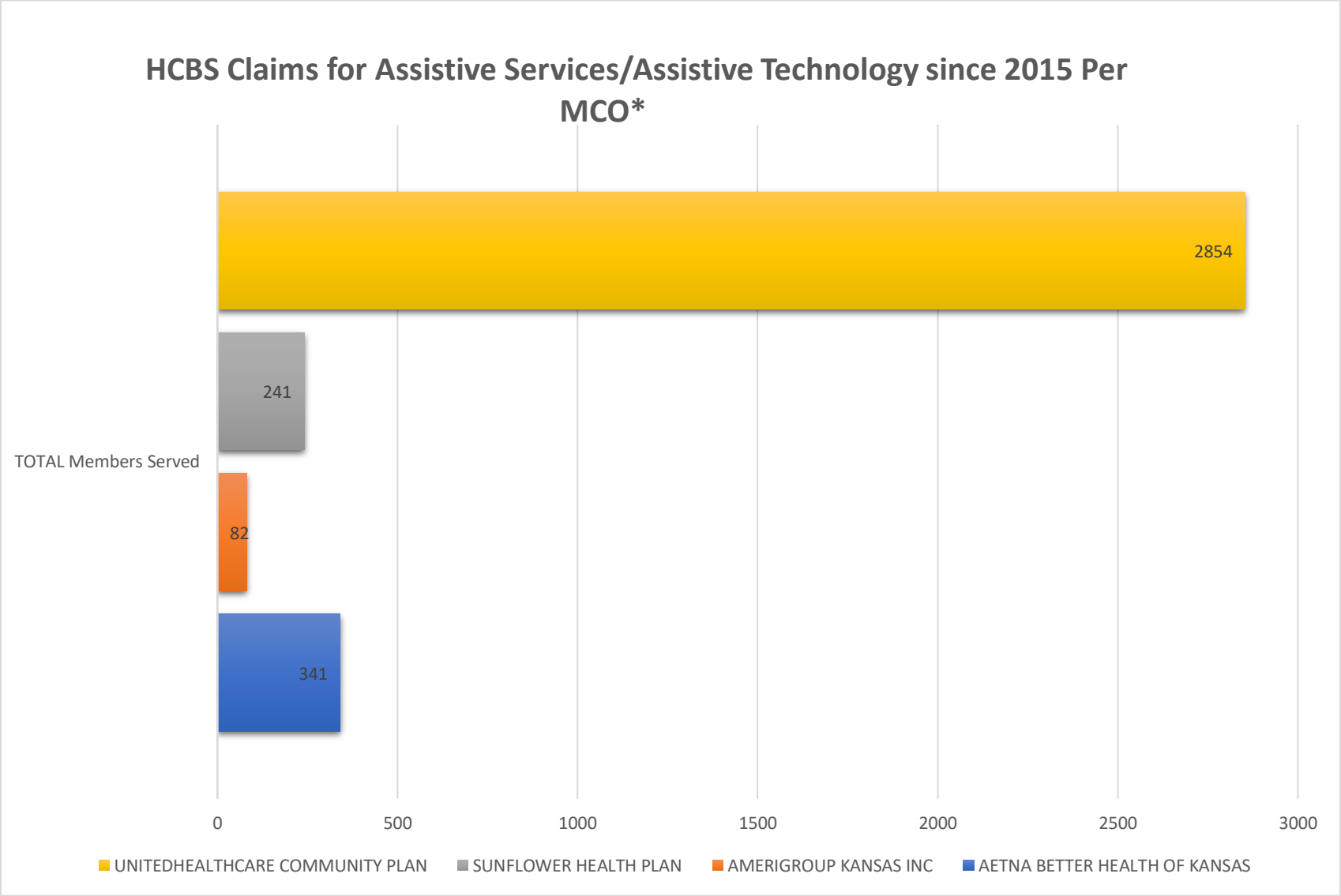
The below charts are made from data received from Kansas Legislative Research listed on pages 8-12

CHART # 1



Note: Total Expenditure from 2015-present; Sunflower is: $934,238.92; United is $6,762,381.34; Aetna is: $2,313,057.99 (2019-present)

CHART # 2



Based on the data:

United completed 81.1% of all claims; Aetna completed 9.7% of all claims; Sunflower completed 6.9% of all claims and Amerigroup completed 2.3% of all claims. **Aetna's data is from 2019-2023**. United and Sunflowers data reflects from 2015-2023.

CHART # 3

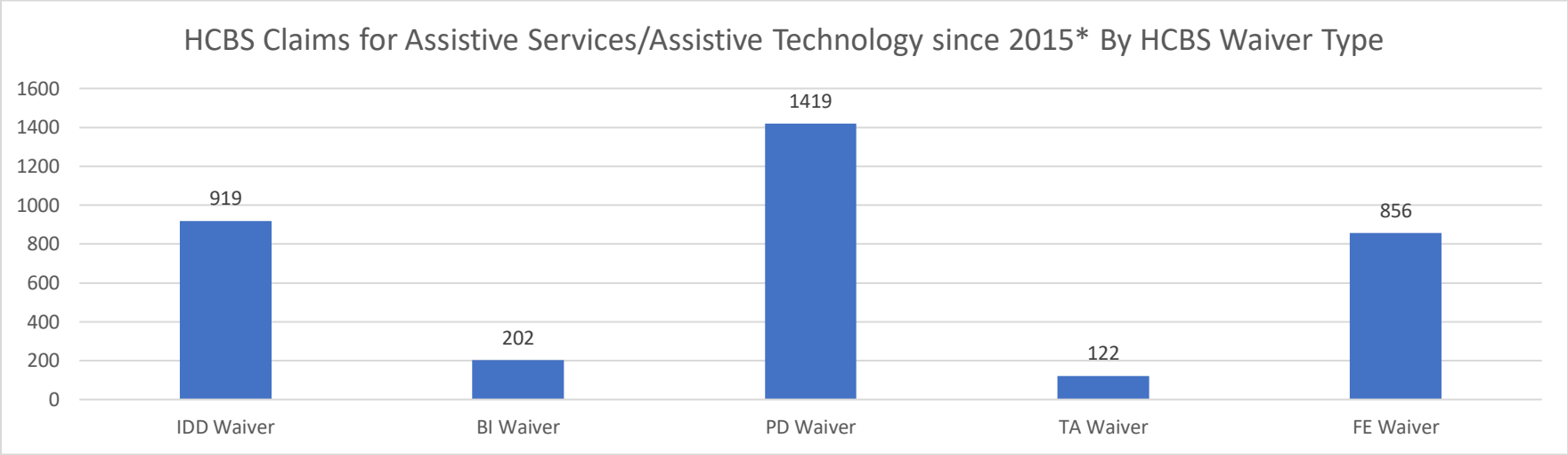


CHART # 4

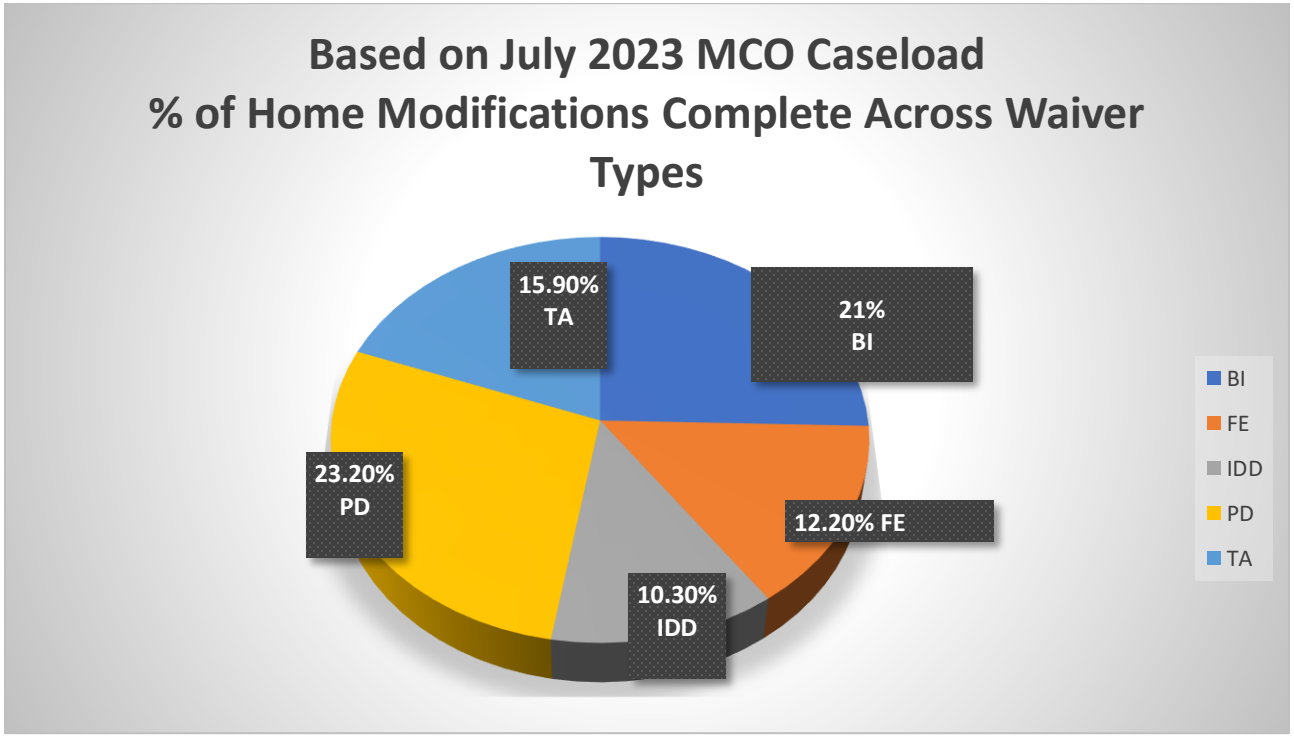
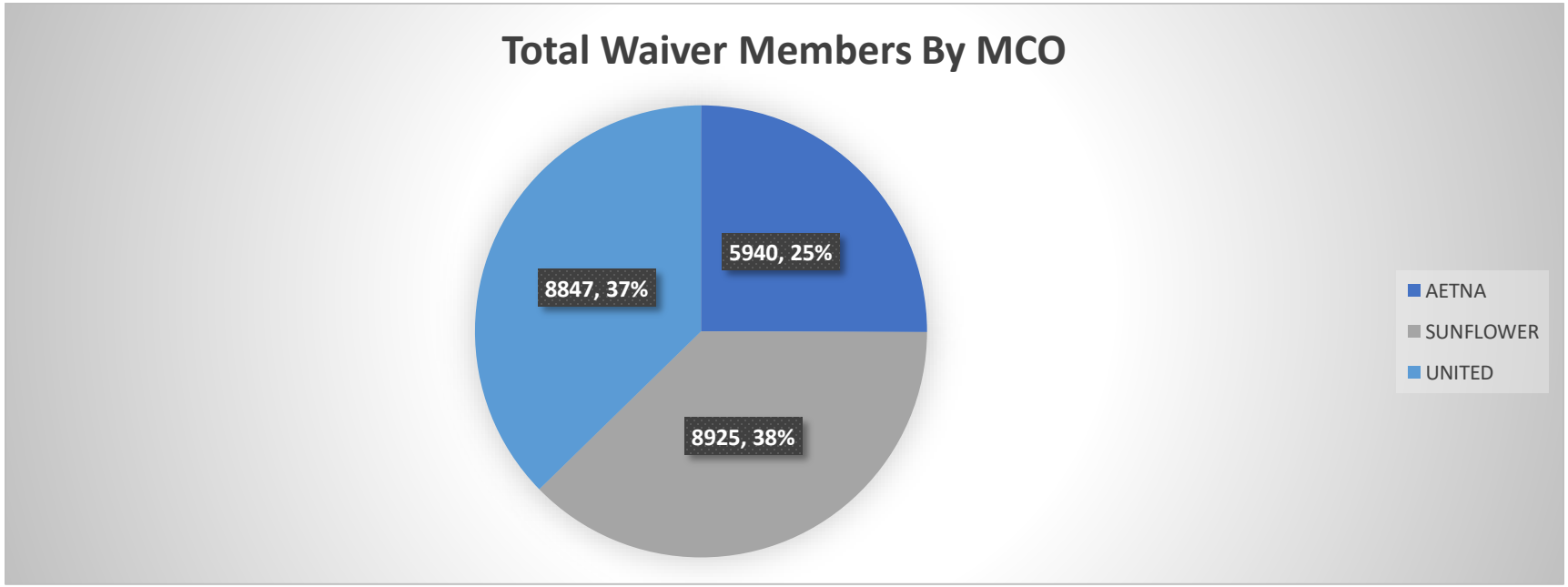


CHART # 5

% of Members Per MCO on each Waiver according to July 2023 Caseload

HCBS Waiver	Aetna		Sunflower		United		Grand Total
	# Participants	%	# Participants	%	# Participants	%	
AU Waiver	17	27%	17	27%	30	47%	64
BI Waiver	320	33%	216	23%	423	44%	959
FE Waiver	2,167	31%	1,878	27%	2,949	42%	6,994
I/DD Waiver	1,434	16%	4,677	53%	2,769	31%	8,880
PD Waiver	1,814	30%	1,926	32%	2,373	39%	6,113
SED Waiver	971	29%	1,188	36%	1,139	35%	3,298
TA Waiver	205	27%	228	30%	333	43%	766

CHART # 6



Note: Sunflower has the highest number of Waiver participants and the lowest % of claims at 6.9%- see chart on page 2

Information received from Legislative Research

Q: How many providers do each of the MCOs have to do home modifications under an HCBS waiver?

Aetna

We currently have 5 providers that we contract. There are 3 (Thrive, Lifewise and Accessible Rehab Works) that cover the entire state.

Sunflower

We currently have 33 providers enrolled to provide Home Modifications. With that said, we primarily work with 10 providers who do the bulk of the home modifications. Referrals are driven by member choice and availability of the provider to serve the area of the state in which the member resides. We work closely with these providers to ensure they follow the requirements outlined in the HCBS Waivers and that the documentation and home assessments indicate how the modification will safely meet the member's needs.

United Health Care

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Q: How many providers did Kansas have for the same type of home modifications prior to privatization/KanCare?

Below are the number of providers billing for the Medicaid code S5165 which covers Assistive Services.

CY2012, pre-managed care: 40 providers had claims for S5165

CY2022: The following number of providers have billed MCOs for S5165 in CY2022:

- Aetna: 9
- Sunflower: 8
- United Health Care: 16

Notations:

- The FE Waiver does not have S5165 but does have T2029, however T2029 is not included in these numbers.
- Here's the service definition for Assistive Services (S5165): Assistive services are supports or items that meet a participant's assessed need by improving and promoting the person's health, independence, productivity, or integration into the community. They are directly related to the participant's PCSP with measurable outcomes. Examples include, but are not limited to,

wheelchair modifications, ramps, lifts, modifications to bathrooms and kitchens (specifically related to accessibility), and assistive technology (items that improve communication, mobility, or assist with activities of daily living or instrumental activities of daily living in the home and workplace). The assistive service must do one of the following:

- Increase the participant's ability to live independently
- Increase or enhance the participant's productivity
- Improve the participant's health and welfare

The definition is not verbatim across all waivers, but the overall process and intent remains consistent.

With the pending amendment approvals, KDADS will be unbundling Assistive Services into three distinct services:

Specialized Medical Equipment and Supplies (T2029)

SMES includes payment for items like assistive devices, communication tools, and life-support equipment specified in the Person-Centered Service Plan. These help participants with daily living activities, environmental interactions, and addressing physical conditions. Examples might be special communication boards for those with speech difficulties, devices to aid mobility, or specific equipment for life support. The coverage/provision of SMES furnished through this service shall include the costs of maintenance and upkeep of devices and training on the utilization of the devices. This includes normal wear and tear. Intentional destruction or damage to devices will not be a covered cost.

Vehicle Modification Services (T2039)

VMS may provide funding for modifications to participants' vehicles, such as the installation of lifts and ramps. These modifications are designed to help participants get around more easily and independently. For example, VMS could be used to install a wheelchair lift in a participant's van, or to install ramps in the back of a pickup truck to make it easier for a participant to load and unload their wheelchair. Certain exclusions apply including but not limited to: vehicle maintenance and repair, purchase or lease of vehicle, improvements that are not of direct medical or remedial benefit to the participant, and vehicles that are not registered under the participant or other legally responsible parent or guardian.

Home and Environmental Modification Services (S5165)

HEMS may provide funding for physical modifications to participants' homes, such as the installation of grab bars, ramps, and railings. These modifications are designed to help participants live more independently and safely in their homes. For example, HEMS could be used to install a ramp to make it easier for a participant in a wheelchair to get in and out of their house, or to install grab bars in the bathroom to help a participant with mobility issues get in and out of the bathtub. HEMS adaptations exclude general utility improvements to residences, additions to home square footage (unless directly related to participant access), legally mandated improvements, generators not linked to medical devices, and traditional shafted elevators.

Q: Can you clarify how this process works for individuals who request home modifications? Are there any differences between waivers and the application/process for home modifications? Are there any differences for minors and adults when home modification is requested?

Aetna

The process is the same regardless of the waiver or age of the member. However, each waiver does have specific lifetime limits, other than the IDD Waiver, which is unlimited. Most of the limits are currently set at $7500, which is set to increase to $10000 effective 9/1/23. We obtain a signed homeowner authorization form, obtain 2 bids, verify if they meet the benefit exception criteria and take through SDR for approval. Most of these are ILO approval as they either don't meet the benefit exception criteria, or they are over the $7500 lifetime limit. Prior to the June announcement from KDADS we were required to explore community resources. However, this has been put on hold unless the member specifically requests assistance with community resources.

Sunflower

The process for requesting home modifications is the same for all members who are on a HCBS Waiver. Members can request home modifications through their Care Coordinator. Typically, the Care Coordinator identifies home modification and assistive service needs during the assessment and person-centered service planning process. The Care Coordinator shares waiver requirements and gathers documentation prior to a decision. This can include a notarized approval letter from a landlord, prescription from a medical professional, medical records, and photos. It may also include an assessment by a physical or occupational therapist if the service required to meet the need is unclear. The Care Coordinator provides education to the member on the process and timelines. Once the information is obtained, the plan identifies multiple providers to deliver competitive bids and manages this process. After this information is returned and a request is considered complete, it is submitted for a final decision by the plan. The plan will then issue a decision letter and if approved, an authorization will be sent to the provider. Additional details are included in the attached work process.

United Health Care

- Process:
    - Member requests home modification;
    - CC requests home modification with program manager;
    - Program manager reviews request and Appendix C of the member's current HCBS waiver application;
    - Program manager makes a recommendation to Medical Director for approval or denial;
    - Medical Director issues decision;
    - Program manager notifies CC;
    - If denied, program manager issues a notice of adverse determination/notice of action w/ appeal rights for the member,
    - If approved, program manager requests bids from two service providers (one if two are not available in member's area);
        - Service provider provides a bid for scope of work requested;
        - Program managers reviews bids with medical director

§ Contract is awarded to provider based on: bid cost, work quality, solution recommended, with member preference considered as a factor

- Each HCBS waiver (BI, FE, IDD, PD, TA) have their own wavier criteria for considering approval for a home modification. Each of the HCBS waiver criteria is detailed in Appendix C of the HCBS waiver and includes: service description, service limitations and provider requirements. Appendix C is specific to each waiver population and is not the same across all waivers.

The service criteria of Appendix C of each waiver applies to the entire population for that HCBS waiver (adult or child). If the individual is coded for and receiving services through a waiver and requests a home modification, the service detailed in Appendix C and the service limitations will be considered and applied the same no matter whether the waiver recipient is and adult or a child.

Q: The number of home modifications completed since 2015.

HCBS Claims for Assistive Services/Assistive Technology since 2015*					
HCBS Waiver	AETNA BETTER HEALTH OF KANSAS	AMERIGROUP KANSAS INC	SUNFLOWER HEALTH PLAN	UNITEDHEALTHCARE COMMUNITY PLAN	Statewide
IDD Waiver	65	41	143	670	919
BI Waiver	33	22	16	131	202
PD Waiver	127	9	50	1233	1419
TA Waiver	20	3	20	79	122
FE Waiver	96	7	12	741	856

*Assistive Services/Assistive Technology Services includes supports in addition to home modifications.

Q: If the modification was done under EPSDT or under a waiver, which waiver.

Annual Expenditures for Assistive Services/Assistive Technology since 2015 By MCO By Waiver*									
	AMERIGROUP KANSAS INC				AETNA BETTER HEALTH OF KANSAS				
HCBS Waiver	2015	2016	2017	2018	2019	2020	2021	2022	2023 to date
IDD Waiver	$5,550.00	$22,594.96	$130,928.98	$165,626.36	$49,502.80	$42,481.58	$153,645.05	$229,823.47	$51,450.00
BI Waiver	$10,362.84	$7,295.95	$43,336.62	$915.65	$31,287.94	$9,041.84	$21,073.48	$72,521.44	$10,039.45
PD Waiver	$1,050.00	$660.30	$12,150.00	$15,011.05	$16,041.25	$43,175.42	$97,569.76	$191,716.75	$151,015.00
TA Waiver		$10,972.00		$7,500.00		$6,113.00	$12,625.00	$22,331.00	$57,880.50
FE Waiver		$594.95	$7,105.00	$2,852.40	$1,758.99	$5,461.83	$113,319.75	$201,620.89	$124,389.18
Grand Total	$16,962.84	$42,118.16	$193,520.60	$191,905.46	$98,590.98	$106,273.67	$398,233.04	$718,013.55	$394,774.13
	SUNFLOWER HEALTH PLAN								
HCBS Waiver	2015	2016	2017	2018	2019	2020	2021	2022	2023 to date
IDD Waiver	$42,088.02	$79,532.70	$65,117.72	$59,215.61	$97,172.50	$84,943.98	$78,459.87	$74,734.46	$58,097.85
BI Waiver		$210.00		$250.00	$7,502.00	$8,266.35	$10,669.66	$3,898.84	$35,156.12
PD Waiver	$1,968.48	$9,897.16	$8,554.33	$3,711.74	$6,002.77	$1,200.00	$621.50	$52,029.52	$31,561.00
TA Waiver	$850.00	$3,335.00	$8,385.52	$35,205.38	$3,508.74	$600.00	$0.00	$5,647.19	$4,687.50
FE Waiver		$5,342.50						$36,224.91	$9,590.00
Grand Total	$44,906.50	$98,317.36	$82,057.57	$98,382.73	$114,186.01	$95,010.33	$89,751.03	$172,534.92	$139,092.47
	UNITEDHEALTHCARE COMMUNITY PLAN								
HCBS Waiver	2015	2016	2017	2018	2019	2020	2021	2022	2023 to date
IDD Waiver	$117,458.71	$383,160.83	$234,591.77	$214,267.88	$364,340.52	$204,426.91	$275,604.96	$272,569.81	$253,271.51
BI Waiver	$5,190.50	$5,444.89	$667.40	$10,955.30	$16,894.92	$25,945.82	$117,162.26	$108,744.10	$19,773.01
PD Waiver	$99,520.75	$319,521.01	$468,942.82	$212,381.13	$261,734.60	$217,822.07	$243,006.72	$297,537.53	$165,535.07
TA Waiver	$10,017.50	$33,738.49	$18,199.75	$26,088.00	$33,168.60	$22,028.00	$50,701.13	$130,382.04	$46,510.00
FE Waiver	$77,545.38	$167,571.97	$269,744.46	$190,226.94	$68,812.18	$125,454.00	$155,011.28	$201,916.10	$218,792.72
Grand Total	$309,732.84	$909,437.19	$992,146.20	$653,919.25	$744,950.82	$595,676.80	$841,486.35	$1,011,149.58	$703,882.31

*Assistive Services/Assistive Technology Services includes supports in addition to home modifications.