

Dear Senator Schmidt,

I am writing to make my support known to terminate any request to the United States centers for medicare and medicaid services to administer intellectual or developmental disability services, community service coordination and services provided by intermediate care facilities for persons with intellectual disabilities through a managed care delivery system and shall cease administering all such services through a managed care delivery system pursuant to a waiver granted by the federal centers for medicare and medicaid services under section 1115 or 1915 of the federal social security act, or any combination thereof.

(Question poised to me by CMS/CMCHO) “Usually, in HCBS waivers, a person is considered to have a conflict of interest if s/he is paid to provide services to a participant, and also has authority to decide what services are provided or who will be paid to provide them.” How does this not apply to MCO care coordinators?

My answer:

- a) MCO care coordinators work for the MCO’s to provide services to a participant.
- b) MCO care coordinators have authority to decide what services are provided on the participant’s integrated service plans.
- c) MCO’s care coordinators conduct’s needs assessment of waiver participants. “Limitations on the amount and type of waived services are governed by the MCO’S assessed need of the participant and monitored by
- d) the participant's KanCare MCO”.
- e) MCO’s make their profits from cost saving.
- f) MCO’s have authority to decide who will be paid to provide services as they contracts with providers of service.

This last year has been a rough one for my family because of Managed Care. Our son who is 35 requires total supports in all needs and night support for oxygen on the IDD waiver.

In January of 2017 Amerigroup decided to no longer pay for the brand of incontinence supplies that they had agreed to pay for under a 2013 ADA agreement. However no one told me it was a cost issue just that the provider no longer carried that brand. So I requested a new provider for the branded incontinence supplies from the care coordinator. The care coordinator told me she could not find a new provider and I should pay out of pocket for the brand I needed. It cost us \$ 60.00 a month for the branded incontinence supplies. It took 11 months and 3 grievances to get Amerigroup to honor the 2013 ADA agreement.

Then in April 2017 we had billing problems with the oxygen supplier I reached out to care coordinator for support and was told it was outside her scope of services. We had our weekend night staff quit as well over needing more money. Made the request to move 6 hours of the 12 hours of Personal Care Services to Enhanced Care Services to care coordinator, was told that was unrealistic by care coordinator, but if that was what I wanted a new

need assessment would need to be done. I agreed to the assessment care coordinator said she was handing my son's case off to new care coordinator.

May 2017 2 care coordinators (2) came for need assessment. I was asked to start from the beginning I asked if they had read my son's person centered support plan I was told that they did not want to be tainted by my son information. I ended the meeting and walked out.

Needs assessment was not completed and Enhanced Care Services were denied. I am so mad and overwhelmed at this point I cannot think straight. Took the denial of Enhanced Care Services all the way to fair hearing. During the hearing process a KDADS team reached out to me. By this time I understood I did not complete the process and cannot win the hearing and a rate increase had happened. I withdrew from hearing. It is now September, received email from the care coordinator that used the word tainted for a 6 month review. I did not want to meet with him. His response was if I refused to meet with him for the 6 month review, Amerigroup will be unable to be in compliance with state regulations and therefore my son may lose his insurance because it will prevent Amerigroup from completing their agreement with the state contract. Now I am mad again, I had never heard of this 6 month review requirement before. I feel threatened by this care coordinator that used the word tainted. If my son loses his insurance he could lose his life. I start emailing asking questions of our CDDO, KanCare Ombudsman's Office, James Bart, Paula Morgan, Amy Penrod, Shirley L. Norris none of who ever replied as to whether the care coordinator could end my son's insurance and services. I emailed CMS ask them for guidance was told that without a review at some point my son's waived services would end but his health insurance would not be effected. My son's ISP had an end date of February 28, 2018. So I did not respond to care coordinator's meeting request.

December KanCare Ombudsman's Office did reach out and help me get Amerigroup to find a provider and pay for the branded incontinence supplies. DRC helped me get Amerigroup to provide reimbursement for what we paid out of pocket for branded incontinence supplies.

January 2018 called Amerigroup and requested a new care coordinator. Amerigroup in turn requested a meeting with me. I became enlightened at this meeting.

1. Found out that when KDADS team reached out to me it was because I was reported for possible fraud.
2. That the reasons branded incontinence supplies were not being covered was because the cost is more than the generic brand. But not one person knew this in the LTSS department and Amerigroup had agreed and paid for
3. the branded incontinence supplies for 3 years. I heard all about how branded incontinence supplies were costing Amerigroup money.
4. Amerigroup needed a guarantee I would meet their 6 months review requirement. My response was if someone is refusing to meet with care coordinator than they might need to ask themselves why. That the state had
5. never responded to my question about the 6 months review requirement and to date I questioned their ability to end services based on not meeting that requirement. Amerigroup's response was something about that the

6. state doesn't even know how to write up a corrective action anymore how could they understand this.
7. I heard all about this was open enrollment and a new care coordinator might not be possible. My response was I was not meeting with the care coordinator that used the word tainted or threaten my son's services. Learned
8. the email response that I found threatening was written by his boss, and she saw nothing wrong with the email. My response was that according to CMS there was a difference between waiver services and insurance. Boy
9. were they mad that I had emailed CMS.
10. I also made the statement that I would no longer sign a blank I pad because I had lost trust in them, and from what I had read in the March 2016 approved waiver a paper copy should be provided to me at the time of the
11. meeting. Amerigroup said I was wrong. We agreed to both go back and look up what was written in the waiver.

January 26, 2018 Amerigroup assigned a care coordinator and we started talking about a meeting time for ISP. I reminded them that I had looked up the March 2016 approved waiver and it did state that a paper copy should be provided to me at the time of the meeting. Their response was there would be no paper copy provided at the meeting and I did not need to sign anything. Reason for no paper copy was it would take 4 or 5 hours to do the need assessment and ISP.

February 7th had ISP meeting for new ISP and needs assessment meeting started at 9am ended at 1:26pm. I did not sign and anything. Here what I learned.

1. Amerigroup offers I/DD waiver members get three extra days of PCS. As added benefit. When I asked about this I was told that it was only for self directed members because a FMS provider was needed to access this service
2. my son has agency directed PCS. This is discrimination and wrong.
3. Capable person policy the way they do this is upsetting to me. MCO's do not want to not pay for services like cooking, cleaning, laundry, escort to medical appointments, and don't want to put them on the ISP even when the
4. person needs are total supports 24 hour care. I believe in the Capable person concept as a family we do provide unpaid care already. Our son needs are total supports 24 hours 7 days a week he has paid services for 17 hours a
5. day 5 days a week and 12 hours a day on the weekends. As a family we provide 59 hours a week of unpaid capable person services. I do not understand why these hours do not count as capable person services. These kind of
6. rules were never applied before managed care.

I am writing this at 1am and have not proof read it all so please forgive any mistakes, I tired but wanted to share my experience of the last year with you in hopes you can read it before your hearing tomorrow.

Thank you,
 Robbin Allen
 Newton, KS
 316-282-0099

