

To whom it may concern:

My name is Laura Kozisek, Mom of a 20 year old who is developmentally 6 years old. As Jackson continues to age, the challenges of caring for a dependent with developmental disabilities continue to grow. Below are just some of the items that are stressors in families like ours. We are blessed to have jobs that allow us to care for our son, but not all families have these resources available. As Jackson ages, our ability to continue to work with become diminished based upon resource availability.

Care Challenges:

1. Local Medical Care - In terms of receiving care, we have been lucky in that we have insurance through our employer with a secondary in Medicaid. For those who are Medicaid only, unless you are established, many of the independent practitioners are not willing to accept Medicaid due to the low reimbursement. Again, we have been lucky as we utilize providers that are employed through large health systems, however, the individual practitioners in the market can not afford to accept our dependents as their medical needs can be extensive with limited reimbursement for the time they spend.
2. Out of Area Medical Care – For individuals with somewhat rare disorders, we are often required to travel to receive the appropriate expertise in our diagnosis. Since Medicaid is a state run program, we are often required to pay out of pocket for any services received outside the state in which we live as there is no collaboration between states. For families, this can be financially draining. For example, our son has Tuberous Sclerosis (TSC) . While there are neurologists that treat seizure disorders in Kansas City, there are TSC Clinics that have been involved in research programs specific to TSC, however, they are located in other states to include Missouri. We will be required to pay out of pocket for services not covered through our primary insurance and not covered through our Medicaid. Many families can not afford to provide this level of care.
3. Providers out of area – Because there is no reciprocity between states, providers who accept patients outside of their state, they are required to either write off the service or apply/participate in the specific state Medicaid program in order to be paid. If the patient has an MCO, then the provider is required to apply, complete an application, go through a 60-90 day credentialing process and then sign an Agreement with the MCO. This is very time consuming, especially when there are minimal patients coming from other states.

Resource Availability:

1. Required documentation – Families who have dependents struggle with managing time. Many of our children require around the clock care, yet we are required to comply with quarterly meetings with the MCOs and completion of daily tracking tools for our children. The expectation is that we track seizures (when applicable) and behaviors on a daily basis. While I understand the importance of keeping track of whether our children continue to need care, after so many quarterly meetings with limited to no change, this becomes a challenge on the families, especially those families that are required to have 2 working parents. Our son is 20 but developmentally 6. He has not progressed for years and yet we are required to ensure that he still meets state qualifications. This takes time away from my work and interrupts his daily schedule each time we are required to meet.

Day Programs: A completely different concern that we have as parents involves care after a child has aged out of the school system. I understand that there are limited resources, but the impact on a family of working parents is quite challenging. Below are some key issues associated with day programs:

1. Availability of programs - There are limitations that challenge working parents.
 1. availability for these kids/young adults,
 2. waiting lists,
 3. daytime services that are available only until 3:00 while parents work until 5:00
2. Transportation –
 1. Medical - There is transportation built into the benefits for the population to have visits to and from a physician, however, for the developmentally delayed population, this is not a benefit as we would not send our dependent to a physician visit without a guardian/caregiver. Therefore, while this is an added benefit in the benefit design, it is not something most families would utilize for their developmentally delayed dependent.
 2. Day Programs – Day Programs allow the guardians the ability to work, however, unless the dependent is going to a work program, there is no transportation available. If there is a work program, there is limited transportation is available. The resources are similar to that of the general public which presents safety concerns for this population. Many of our children do not have the ability to stand up for themselves or know when someone is taking advantage of them. In addition, many of these transportation programs may require them to spend an hour each way in a van due to limited resources and low pay. During high school, we had a service for our children that was door to door. When approached as to whether they would transport our children to day program, they informed us that the reimbursement did not cover their costs and therefore, they were unable to provide this service. Consistency with this population is key.
3. After Program Resources – Many of our dependents need around the clock care. Resources are limited in terms of finding help. For those who can utilize a day program, we will continue to need assistance for the remainder of our work days. Finding people who can provide this care is extremely difficult and unpredictable.

Residential Supports: Groups homes are predominant with the developmentally delayed population. There are several challenges with this type of living arrangement from a parents perspective:

1. Caregivers – The caregivers are very fluid in these situations as they are not highly paid individuals. For our population, they need consistency and extra care provided. When caregivers are continually changing, there are mistakes that can be made. Many of our dependents require medication for medical and/or behavioral needs. I have witnessed personally medication errors due to high turnover at residential homes that have resulted in seizures and/or behavioral outbursts putting these individuals and others around them in harms way.
2. Alternative Care: I have been trying to identify what is a location in which our son can thrive as he continues through his life journey. He wants to become “independent” as he ages, however, he requires quite a bit of care in terms of medication and general assistance to ensure he is safe and well cared for. I would love to see a situation where our young adults could live in a similar to that of a “dorm type setting” where they have caregivers available to them, but can also assist in the day to day work that needs to occur within their living environment. In other words, they could help wipe down tables, stock the kitchen, simple cleaning, etc. They could each have a small “dorm” type room, but still have oversight by a care team. They could have hot meals, work outside of the living environment, and have their friends and activities within

the “home”. It is my understanding that the state of Kansas views this as institutionalizing our dependents, however, I believe it would be a safe place and potentially a reduction in the costs associated with caring for our children. It also allows our children to have multiple individuals caring for them vs a single individual as in the situation with residential homes. This is something I would love to explore further, but I am not sure how to go about obtaining data to support my thoughts. I have spoken to other parents who prefer this model as they feel there is then oversight on our children, more consistency in staffing, and peers in which they can interact. I would love to speak with someone more about this concept.

Thank you for your time. Please feel free to reach out with any questions/comments you may have.

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