

“Disability only becomes a tragedy when society fails to provide the things needed to live one’s daily life.” Judith Heumann

These comments are submitted on behalf of my adult son, Joel, and others receiving services through the Individuals with Disabilities (ID) waiver program. I attended your committee meeting on Friday, November 30, 2018, and listened to Secretary Foxhoven and Mr. Randol describing how well managed care is working for Medicaid recipients. I don’t doubt this is true for some but managed care is NOT working well for the most vulnerable Medicaid recipients like my son.

Iowans were told managed care would result in savings, a robust provider network, access to needed services, and improved outcomes. According to DHS and a recent report from the Auditor it appears there have been savings. However other expected outcomes have NOT been realized, especially for recipients who receive supports and services through one of IA’s home and community-based waivers.

Following are suggestions for your consideration to resolve concerns that persist:

1. **Provider reimbursement rates** must be sufficient to support an adequate provider network; to ensure individuals with disabilities have access to individualized support services to meet their unique and complex needs; and so providers can hire and retain quality Direct Support Staff.

Reimbursement rates remain insufficient. Some providers went out of business and others decided to stop participating in the Medicaid program, which has restricted choice and access to services. Others have been forced to consolidate services resulting in less individualized services and disruptions that are more difficult for many individuals with disabilities. Providers have consolidated waiver homes supporting 2-3 individuals to 5-6 person homes forcing people to move and changes in support staff. “Alone time” (no support staff present) has also been increased in some homes, which could jeopardize the health and safety of residents. Recipients have been forced to move into more restrictive (institutional) settings.

Providers continue to experience a shortage of qualified Direct Support Staff that impacts access to services and the quality of services.

2. **Case management** services must be transitioned back to independent agencies NOT affiliated with the MCOs to increase stability of the service and to remove any real or perceived conflict of interest in the development and approval of service plans.

Increased case loads under MCOs have resulted in less frequent contacts and some recipients have experienced frequent turnover. Both impact the quality of this critical service. Also concerns persist that cost-savings and profits for the MCO are

considered when developing service plans and allocating resources, which erodes the trust and confidence between recipients and their case managers.

3. **Accountability** requires a cost analysis showing more than an aggregated cost number. A cost analysis must be done that also shows the cost of specific services for specific groups of people both before and after managed care implementation. Data on improved outcomes (health and non-health) for **ALL** recipients must also be tracked and reported.

In addition to the cost of services it is important to know how savings are achieved, including: a) changes in services and what those changes are; b) changes in eligibility; and, c) the impact of these changes on recipients. Mr. Randol, in response to questions, did cite improvements such as fewer ER visits and less frequent/shorter hospitalizations as a result of better care for recipients with chronic health conditions (diabetes, asthma, high cholesterol) including preventative care. However, I did not hear specific improvements in non-health related services such as those provided through home and community-based waivers (supported community living, employment, case management, transportation, etc.) and better outcomes for people receiving those services.

Finally, parents like me understand and support the need for sustainability in the Medicaid program to ensure our sons and daughters have access to needed supports. We also understand the equal need for an **effective** program where our sons and daughters have access to individualized services to maximize their independence and to ensure their health, safety and well-being. Restricting access to needed services is NOT cost effective over time.

My husband and I are both 65-years of age, and the day is approaching when we will no longer be able to be primary caregivers for our son. What is to become of him is my biggest fear and keeps me up many nights? We are doing everything we can to plan for that reality and leave resources that can help support him. However, Joel will also need the specialized supports and services of the Medicaid program. I hope that policymakers will work with individuals, families, and advocates to design and support a Medicaid program that is sustainable AND will support Joel to live in his own home close to family and friends who will provide natural supports when possible; to be employed; and to be involved in community activities he enjoys and enrich his life.

Respectfully submitted by Kay Marcel
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