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Re: Shared Living Arrangements and Discrimination

Dear

Families of adults with special needs (Persons with Disabilities/PWDs) in Nevada are struggling to care for their loved ones and, in some cases, being discriminated against.

A current program under Policy 41-6 Shared Living Arrangements allows PWDs to live independently in the location of their choice. This policy has benefitted many. Under this policy, if the PWD is living with the Legally Responsible Individual (family member that is also the guardian of the PWD), then the family member/guardian cannot be compensated as a caregiver unless they relinquish guardianship. This rule states:

- Legally Responsible Individuals (LRI): Persons who are legally responsible to provide medical support, including spouses of individuals, legal guardians, and parents of minors receiving services including adoptive parents, stepparents, and foster parents. LRI's cannot receive payment for the provision of residential support services.

There is currently a policy change to Department of Health and Human Services/Home and Community Based Services Waiver Renewal.../Appendix C – Participant Services: “Allow legal guardians of adults to receive payment for Residential Support Services and Non-Medical Transportation”. It is crucial to Nevada families that this policy change is approved and implemented – especially for single parent families.

Scenarios that explain why this policy of not compensating LRIs, while assisting some, is hurting other PWDs and their families:

Scenario 1

A 24 year old male adult with a disability (PWD) chooses to live at home with his family. The father leaves his job to stay home and the mother works. The father is the caregiver and the mother is the LRI/guardian. The family is receiving Shared Living funds. The father passes away and the mother has to quit her job to take care of him. Because she is the LRI/guardian, she cannot access the Shared Living funds they were previously using to get by. She has no family in town to transfer the LRI/guardianship to and she, most importantly, does not want to give up guardianship of her son due to the many legal, financial and safety ramifications that can occur. She would be performing the same tasks under the same supervision that the father did, but she cannot get this assistance because she is the LRI/guardian. Her son's choice is to stay at home and, according to federal laws, his choice should be honored.

Scenario 2

A single parent who is the guardian of her 22 year old son struggles to get and retain in home care providers. Her son receives SLA services. She needs to use sick days (if she has not exhausted them) and risk losing her job to stay home with him when the provider does not come or she cannot find one to hire. She has no one she trusts to transfer guardianship to and become the LRI so she can receive Shared Living funds – which is important as she will likely need to leave or lose her job. She does not want to give up guardianship of her son to receive these services because he has concerning behaviors and is worried what would happen to him without her protection. Her son's choice is to live at

home with her. This also fits with his person centered plan. When she can find providers, she is the one who trains and supervises them in the home. It does not make sense that, under these regulations, the State would rather hire someone that does not have training or experience, who does not know her son and who will likely leave in under a year...instead of providing funds to the person that knows him best, understands his needs and does the training so he can remain in the home of his choice and she can make ends meet without employment. The choice of the PWD and what is in the best interest of the family is to allow the LRI/parent/guardian to receive the funds.

Basically single parents, who need the most support, are being discriminated against.

Single parents taking care of adult family members with disabilities, most whom are trying to work, are the ones who need the most support. Yet they cannot access this program and have few, if any, other supports available. Giving up guardianship of a loved one you are taking care of day to day presents challenges in the areas of legalities, medical care (as that is the person that would be going to the doctor with the PWD) and finances. They should not have to make the choice between paying bills or ensuring their family member has a choice of where they live and the best care.

Additional information supporting this change:

1. There are already checks and balances in place – whether it is a guardian/parent/family member or someone that has been hired and trained – to maintain quality of care and programming. So this would not cause any concerns as far as quality of care
 - a. Allowing the PWD to live at home and changing the regulations so the LRI can access these funds saves the state money as opposed to a 24 hour care placement
2. If families, who have a family member who is able to stay home with the PWD and not be the LRI, are able to receive this funding, *then families with a single guardian/parent should also be able to access this funding.*
 - a. This could even be on a case by case basis. For example, if the PWD has behaviors or special needs that make it difficult to find a caregiver, then this issue could be a parameter for qualifying them for the program
 - b. This actually seems like discrimination...families who have more resources and people in the home to care for the PWD can receive help, but single parent/guardian families who are struggling cannot.
3. It is difficult to find caregivers. The argument is sometimes “well, that family member chooses to stay home with the PWD” when in actuality, it is often not a choice. The family cannot find caregivers, is on a wait list, has difficulty retaining caregivers, etc. The family wants what is best for the PWD and wants to honor their choice to live where and with whom is best for their needs.

This policy change should be approved so an LRI/guardian can receive this Shared Living funding to allow the PWD to have the choice of living where and with whom they want to live, including their LRI/guardian/family members. Changing this policy would also prevent discrimination against single parent families and comply with the Olmstead Act. This policy changed allowing LRIs to be compensated can keep PWDs at home, if that is where they choose to live, as opposed to a 24 hour home or more restrictive setting, ***actually saving the taxpayers money.*** The oversight systems are already in place. This allows the family to stay together and the PWD to have the choice of where they live and who takes care of them, while also ensuring the state is complying with federal laws.

We hope you will advocate with us to change the discriminatory issues with this otherwise beneficial program. Shared Living has benefitted many, but should ethically be available to all.

Thank you in advance for your time and efforts.

Sincerely,

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