Important information about a change in practice to guardians and representatives of adults with developmental disabilities

Families often seek guardianship on behalf of an individual with intellectual or developmental disabilities (I/DD) when an individual does not have the ability to make financial or health related decisions. Oregon limits the guardianship authority to these areas (health related decisions = placement decisions, support decisions, etc.). Adults with guardians are not deemed incompetent but unable to make the decisions mentioned above.

What is the change?

Centers for Medicare and Medicaid Services (CMS) does not permit formal/legal guardians or representatives to provide paid supports for an individual who receives state plan Medicaid services. This is the same as the rule for seniors and adults with physical disabilities.

Why is this happening?

CMS considers it a conflict of interest and prohibits the activity under 42 CFR 441.555.

How does this affect Oregon?

As a result of changes to our State Plan and actions required from our recent audit by CMS, we must make programmatic changes in our service system to meet federal standards. One of these changes is the requirement to assure that guardians and representatives are not paid support providers for adults who experience I/DD.

Who does this affect?

This will create a hardship on some families who are the paid support providers as well as guardian and/or representative for the person served. In the past, Oregon allowed these payments to be made, and we recognize that there will be significant impact to some families. We realize the decisions that must be made by each guardian or representative will depend on the personal circumstances and priorities of the family and the person served.

How long do I have to make the decision?

The decision must be in place by December 1, 2013 for January 1, 2014 implementation.

What happens if no change is made by the family/team?

Funding will stop January 1, 2014 -- We do not want that to happen, so we are sending this information out now to ensure everyone has time to discuss, decide and take action.

Are there exceptions?

ODDS may grant exceptions to pay a legal guardian or representative only in extraordinary circumstance, with CMS review, which will require demonstration of certain criteria. The exception policy is currently under development and will be communicated to you when it is completed.

If I am the guardian or representative, what do I need to do?

Families must make a decision whether the guardian will remain in place and *not* continue as the paid service provider and a new service provider chosen, or the guardianship may be terminated or transferred to another person through probate court so the current guardian can remain the paid service provider.

Who can help me if I have questions or want more information?

You can contact your Service Coordinator at your Community Developmental Disabilities Office, or your Personal Agent at the Brokerage that serves you. Although they cannot provide you with legal advice, they will provide the most recent and timely information available to them, review the options for available service providers, and answer general questions.

Does my adult child need to become a ward of the state?

No. A guardianship may either be terminated by the court, or the judge may appoint another guardian. The individual does not need to become a ward of the state.

How can I appeal this decision?

There is no appeal process. This is a federal CMS rule tied to 42 CFR 441.555.

Can I contact someone at the state?

If you would like to contact the state Office of Developmental Disabilities Services directly, please e-mail the Director at: dd.directorsoffice@state.or.us.