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Tamara Prisock
DHW Administrative Procedures Section
450 W. State St., 10th Floor
P. O. Box 83720
Boise, ID 83720-0036

Re: Docket No. 16-0305-0902

Dear Ms. Prisock,

I am writing today on behalf of the Idaho Council on Developmental Disabilities in opposition to the rules proposed in the above referenced docket.

It is our understanding that the genesis of this action was intent language that was part of the Medicaid appropriation for 2010. That intent language, in HB 322, states that *Within this Medicaid appropriation, the Department of Health and Welfare is **requested to proceed** with implementing the necessary policy and operational changes to contain and reduce costs in order to provide for a sustainable Medicaid Program. Key cost containment strategies should include, but are not limited to, the following:*

*(1) Establish costsharing requirements **based on ability to pay** for families whose children are eligible for Home Care for Certain Disabled Children (commonly known as the Katie Beckett Program).*

Although it is clear that Legislature and the Department are taking this action to save funds, we feel that the rules as currently proposed and being implemented are counterproductive to both the intent of the Katie Beckett program to support families with children with significant disabilities and to the legislature's intent to save taxpayer dollars. It is also disturbing to see long-term policy setting via an appropriations bill. This does not permit public input into significant policy changes which will endure long after the appropriations period.

The Home Care for Certain Disabled Children program – or Katie Beckett as it is more commonly called – provides access to Medicaid payment for services for children who have developmental disabilities who qualify for institutional level of care but whose families have chosen to provide that care in the family home. The program recognizes that without this program, families would face an institutional placement for their child at a high emotional cost to the family and a much higher financial burden to the state. The result of this program to families in Idaho is that families stay together and the state saves money over higher cost institutional services.

These rules have an institutional bias. No premiums are imposed upon families if they choose to place their child in an institution. Those families pay none of these costs, costs that are often more expensive. But families of children who stay at home pay some of the costs already and under this proposal will be required to subsidize the program further.

The intent language included in this bill directs the Department to use **“ability to pay”** as a basis for cost sharing. The gross income of a family does not reflect their ability to pay. A family may have a higher income but may also have more than one child with a disability or may have other health or economic situations that significantly impact their ability to pay an additional \$300-400/month for services for their child. I say additional, because many families with children in this program already pay toward their child’s care through out-of-pocket expenses, higher insurance premiums, lost work and a variety of other ways. They have faced the challenge of having a child or children with significant disabilities and made the decision to keep their child at home and their family together. Like other taxpayers, these families understand the importance of using public funds efficiently and only as needed. Many may be willing to participate in a cost sharing methodology if they feel that it is fair and reasonable and takes into account their current financial condition and what they are already doing to pay for the services and care to meet their child’s needs. These rules do not do that. They impose a premium based on a set percentage of gross income. Period. No rationale is provided for how these particular percentages were decided upon. No consideration is given for how few or how many services a child needs and uses. No factoring is included for other costs paid by the family for their child’s care.

Private insurance typically does not cover many of the kinds of services provided through Katie Beckett. That is why the program is so critical. Families maintain private insurance to pay for the health care needs for all their family members. Instituting a premium in the Katie Beckett program may force families to choose between having health insurance for their family or paying this premium to cover some of the therapeutic and developmental services needed by their child with a disability. Do we really want to discourage families from having health care coverage?

The Department has stated that there are children on the Katie Beckett program who do not really qualify for institutional level of care and this results in children receiving services they are not eligible for, driving up costs. However, it is the Department who determines a child’s eligibility and approves their service plans. If the eligibility criteria are inaccurate or inappropriately administered, the problem lies within the Department’s process, not with the families who are seeking support and services for their child.

Has any consideration been given to the cost of administering this program? It has been stated that the child will not lose eligibility if the parent does not pay the premium. However, if the parent does not pay, the Department can pursue collection action. Will additional Department staff be hired to go after parents? Will the Department hire a collection agency? Will parents’ wages be garnished? What will all of this cost? And how does that compare with what the state expects to garner from these premiums? Have projections been made and are these based on the current gross income of participating families?

The Intent language also **“requests”** the Department to **“proceed”** with implementing these policy changes. It does not say implement effective July 1, 2009. The Department was similarly requested to move forward with implementing cost sharing for families with children in the Infant Toddler Program. The approach taken in that program was quite different. Regional meetings were held to gather input and take recommendations about the concept and its potential impact on families. Many recognized that while the state may want to encourage parents to contribute to the cost of services for their child, they did not want to do that at the expense of the child’s health and development. This negotiated rule making approach showed respect and support. The approach used by the Division of Medicaid with these rules is anything but. It is heavy handed and potentially damaging to families and children with disabilities. Had they bothered to take the time to ask parents for their input and conducted due-diligence to determine the costs and benefits of cost sharing, the results might be very different.

Although some families were surprised at this action, there were others who saw that a move in this direction was probably coming. Those families were and are a knowledgeable and valuable resource, able to work with the Department to craft solutions to the difficulties resulting from our current budget shortfall. But unfortunately, by proceeding so quickly with implementation, and surprising and angering the constituency they serve, the Department has alienated these partners.

It is not too late to correct the situation if the Department, with the support of the Legislature, will do so. Before moving forward any further with these rules, stop, and take the time to:

- Research the impact of implementing this cost sharing, both in the short and long term, weighing both costs and benefits to the state and to its families of children with disabilities
- Following the example set by the Infant Toddler Program, engage families in a negotiated discussion of ways to allow people who can to share in the costs for their child's services without forcing them to give up health insurance, not pay the mortgage, or place their child in an institution; consider in this discussion:
 - The impact of parental cost sharing on service utilization
 - The impact of various proposed percentages on parents' ability to pay
 - The use of other than gross income as a basis for determining cost sharing percentage
 - How the cost of family-paid insurance premiums will be used toward meeting these cost-sharing requirements
 - Cost-sharing obligations when there is more than one child with a disability in the family
 - A process by which parents can appeal this premium assessment to avoid collection action for non-payment
- Present this information to policymakers with recommendations based on sound evidence.

Families of children with disabilities in Idaho provide an important part of the foundation of our system of services. Please withdraw these rules and substitute a process that partners with families toward an acceptable solution for all.

Sincerely,



Marilyn B. Sword
Executive Director

cc: Senator Dean Cameron, Chairman, Senate Finance Committee
Representative Maxine Bell, Chairwoman, House Appropriations Committee
Senator Patti Ann Lodge, Chairwoman, Senate Health and Welfare Committee
Representative Sharon Block, Chairwoman, House Health and Welfare Committee
Tammy Perkins, Office of the Governor
Dick Armstrong, Director, Department of Health and Welfare
Leslie Clement, Administrator, Division of Medicaid