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Testimony before the Senate Committee on Health Care on SB 538 Payment of Parents to provide in home care for minor children.

Senator Patterson; Vice-Chair Hayden and members of the committee

My name is Michael Millard, I am usually before you as a pharmacist and professor testifying on a pharmacy related issue. But today I am here as the proud grandparent of Malachi, a child with development disability who receives benefits under this program.

There are many others to discuss the technicalities of the bill, but I would like to make three points as someone who lived this situation and observed the frustration, administrative burden, and heartache parents caring for these children endure every day with strength and love.

First, these children are the most vulnerable of us all. This session many people are using the term "Oregon's most vulnerable population". You are struggling with assistance for the poor, the underserved, the homeless, and the addicted among us. Please remember that these children and their parents are actually and clearly the most vulnerable population among us. These children require constant care and support to maintain day-to-day functioning throughout their lives. They have never taken fentanyl or alcohol, lost a job, or committed a crime. The legislature has rightly provided for their assistance for decades and they should be considered the most vulnerable of all and most deserving of our assistance.

Second, the parents being discussed in this bill are the good guys. These parents are not abusive, neglectful, or too lazy to take care of their own disabled children. These are the parents that are fully committed to the best and highest quality of life for their children. They are dealing with these disabilities with courage, determination, and endurance while facing the challenges presented to them through no fault of their own. They are the best among us, silent unsung heroes who work tirelessly every minute of every day to provide basic life support for their children.

These parents have done nothing to suggest that they seek to cheat the system, defraud the taxpayer, or shirk their parenteral responsibility. The bureaucracy you created at the OHA is capable of monitoring and preventing fraud and abuse that might occur. It is an insult and mistake to base your deliberations of this bill on the baseline assumption that these parents' primary motivation for receiving their full allocation of services as provided by your legislation is financial gain. Also, note that upon a child's 18th birthday, suddenly these same parents can be paid for personal care. Did anything change on this day? The child and the parents and the care needed remain the same.

Finally, the primary motivation for this legislation is to preserve the essential support for this vulnerable group. There is a cruel cycle of declining support for these children. Each family is allocated a certain number of support hours by OHA, based on the child's individual needs. However, the availability of qualified workers is much less than the demand allocated. Therefore, hours allocated cannot be used. OHA appropriately budgets for the hours to be provided but knows at the outset that they will not be used, and funds will remain at the end of the year. OHA can then show that they are "fiscally responsible" by not using all the funds allocated. As a result, in the next biennium less money is allocated because "we don't need it, we didn't use it last time".

This budget shell game must end. The deficit in home care workers and lack of support for disabled children should not be a source of revenue for the state of Oregon. The need for care is constant and essential. Parents can provide these services as responsible individuals who are the child's best advocate.

This bill would not expand the allocated hours or expense to the taxpayer by one dollar. This bill does not increase the support that the legislature has already approved but rather ensures that that support is provided. Thirty-nine states (including Oregon) allowed parents to be paid for some of these hours during the pandemic. Others here today can demonstrate the positive effects this has had on children and families.

I urge (no beg) the committee to approve this bill unanimously and recommend its passage. Show your support for Oregon's disabled children, our most vulnerable population.

Thank You.