**Mark Wax**

**Ohio Senate Health Committee**

**Tuesday, February 19, 2018**

**Proponent Testimony - Senate Bill 29**

I am Mark Wax of Rocky River. I am the legal guardian for our son Andrew Wax, age 26. Our son has been disabled since infancy and suffers from severe autism and several co-morbid neurological diagnoses. Andrew is mentally incompetent by order of the Probate Court and will never live independently. He requires 24/7 care for all of his basic living activities. Andrew first received SSI benefits (at age18) which peaked at $735 per month through 2017. Recently, as I reached full retirement age for Social Security, Andrew was moved to the SSDI Federal Benefit, set at 50% of my monthly benefit. When I die, he will receive 75% of my final benefit.

I asked the legislature to change the law so that people like Andrew would not be required to make any co-pays when obtaining prescription drugs under their Medicaid benefit. Currently, that exclusion is only given to those individuals who are living in an institutional setting. Andrew lives with us a family, which is far better for him and much less expensive than any alternative. Even if the co-pays seem nominal to the average citizen, of perhaps 8-12 dollars on average. This sum may represent an entire day’s food, or an outing to the movies and having an ice cream cup. Andrew was disabled through no fault of his own, should that even matter. Andrew will never have the opportunity to “earn” any money or even understand what money represents.

It may be useful to examine the origins and intentions of Medicaid to properly frame the need for this revised legislation.

Medicaid (Title XIX of the Social Security Act) was created in 1965 in tandem with the Medicare program (Title XVIII).The Medicare program is a federally funded and administered health insurance program for retirees, disabled workers, and their spouses and dependents. In contrast, Medicaid is a *joint* federal-state program through which states, the District of Columbia and the territories receive federal financial participation in their costs of furnishing health and long-term services to federally recognized groups of low-income families and individuals.

Before Medicaid was enacted, limited federal payments were made to states for health care services they purchased on behalf of public assistance recipients. In 1960, Congress authorized open-ended federal matching payments to states for health care provided to indigent older persons.[4](https://aspe.hhs.gov/report/using-medicaid-support-working-age-adults-serious-mental-illnesses-community-handbook/brief-history-medicaid#note2-4) Still, in the early 1960s, states varied widely in the scope of the health care services they funded for low-income individuals and families.

Medicaid was designed to expand access to “mainstream” health care for low-income individuals and families. The federal government would make payments to states to pay for half or more of their costs in furnishing services to beneficiaries. At the same time, the program was framed to give states considerable latitude in fashioning their medical assistance programs. States that elected to participate in the program were required to furnish a core set of basic health services to public assistance recipients. They were also allowed to offer additional services at their option and could elect to serve “medically needy” individuals who did not receive public assistance. Then, as now, the Medicaid program combined federal mandates and state-selected options with respect to who receives services and what services are offered.

The past four decades have seen many changes in federal Medicaid law, including significant modifications in eligibility, benefits, payment arrangements, and other administrative details. The cumulative effect of these changes -- combined with state decisions regarding the scope of their programs -- has been to expand Medicaid well beyond its original focus on furnishing principally acute care services to public assistance recipients. In addition, Medicaid has become the dominant funder of long-term services for people with disabilities. Despite the myriad changes in federal law, the fundamental nature of the programs, the federal-state relationship has not changed appreciably.

There is no escaping the fact that the State of Ohio must serve the disabled before considering any economic considerations that arise from the expansion of Medicaid services for those who may be temporarily experiencing a loss of work, or impacted by the economic dynamics of the marketplace that drives down wages. That is a subject of considerable importance, but it should not be tied to the needs of those whose only source of income is fixed due to their disability or aged (child or elderly) status.

It is not an acceptable solution to simply remove dollars (via the co-pay of Rx drugs) from a Federal stipend meant to provide only the bare minimum standard of living to the disabled. It would be more appropriate to ask the Federal government to change the funding to the states to recognize the special needs of the disabled, as a group.

In 2016, 353,400 individuals (not living in institutional setting) in Ohio, diagnosed with a cognitive disability and receiving SSI, are living below the poverty line. Most will never work, except in a highly sheltered environment earning part-time income.

This revised law is important because it affirms that we as a people keep our solemn pledge to one another. Who will care for us if we cannot care for ourselves? This must not be left to “fate” or the “luck of the draw.” Taking the co-payment from a disabled person’s Federal benefit is merely “lowering” the amount that Ohio is responsible for. The system was not designed to punish someone who has no options.

Please change the legislative rules so that people like Andrew Wax are treated compassionately. Andrew is a citizen of these United States and he is entitled to be recognized for his humanity. He is also the love of my life.