

## **How much would YOU need to earn in order to pay \$188,210 out-of-pocket for nursing care?**

- The SMART Act includes a provision that would create an income cap for the Medically Fragile Technology Dependent (MFTD) Waiver. This income cap would be 500% of the federal poverty line (FPL), or \$95,450 for a family of three.
- The average cost per child in this program is \$188,210. That means that without this program, the average family would have to pay \$188,210 out-of-pocket in order to keep their child at home. Private insurance does not cover or severely restricts private duty nursing care.
- Families would have to pay 200% of their annual income to keep their children at home. It is mathematically impossible for a family of three who earns \$95,450 (500% FPL) to pay \$188,210 out-of-pocket. Even a family who earns double that amount—1000% FPL—could not pay that amount out-of-pocket.
- Children who no longer have access to the MFTD Waiver will need to be hospitalized permanently at three times the cost of home care. This greater amount would still be billed to Medicaid because the federal government mandates Medicaid eligibility for children in institutions. The MFTD Waiver was created for exactly this reason more than 30 years ago—to reduce costs by keeping kids out of hospitals and institutions.
- If only 23 children end up hospitalized permanently, they would erase the entire \$15 million in anticipated savings the state hopes to gain by altering this program.
- This income cap would effectively force children into institutions and hospitals, which is counter to the Americans with Disabilities Act as interpreted by the *Olmstead* Supreme Court Case. Illinois would open itself up to costly litigation on this matter.
- Illinois does not impose income caps on families who choose to place their children in institutions or hospitals, even if they are millionaires, nor on children with developmental disabilities or autism. Only children who require nursing care and whose families make the effort to keep them at home—saving the state money—are being singled out in this way.
- Not one other state has ever imposed an income cap on children with medical technology. This change is unprecedented and returns Illinois to an era when children with disabilities were forced out of their communities and taken from their families.

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