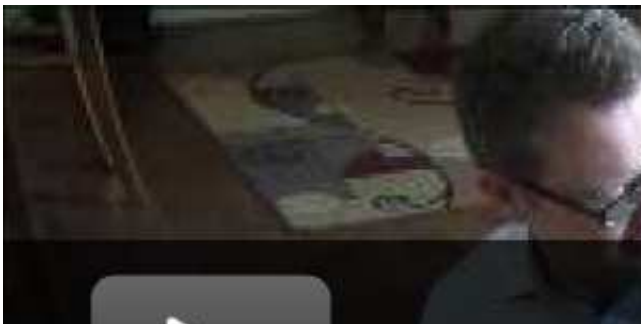




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## **Teen with mind of toddler falls in government aid loophole after father dies**

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LEWISVILLE, N.C. — Max Butkus is one of many children with a disability who are being denied government assistance because one of their parents has died.

Max has mental and physical disabilities due to a genetic disorder called Cornelia de Lange Syndrome. At the age of 16, Max — who is deaf and can see very little — weighs 40 pounds and has the mind of a toddler. His organs are deformed, but they function.

“He is always in a good spirit except when he is sick,” Max’s mother, Robin Butkus, says. “Before he was born they only knew something was wrong with his heart, but his heart was probably one of the strongest parts of his body.”

Max’s father, David Butkus, died last summer at the age of 51 from complications due to a fall. Before David’s death, the family never needed government assistance to afford Max’s medical bills because of the health insurance provided by David’s employer.

In raising Max and a teenage daughter as a widow, Robin has found herself struggling to make ends meet — especially since Max falls in a government loophole that will forever deny him assistance.

Typically, his father’s insurance would have covered him until he was 18. Then, federal assistance known as SSI or supplemental security income for the disabled would have covered everything — including Medicaid.

But because Max’s father died before he turned 18, he now gets a Social Security death benefit. The death benefit is considered income in the eyes of the government and because Max is 16 years old, the government considers him an adult that is able to work and drive.

The government status makes Max forever ineligible for SSI and he must now pay a \$1,200 Medicaid deductible to cover health care. His social security death benefit is \$1,400 a month. After the deductible, Max is left with about \$200 to live on each month for the rest of his life.

“I have to pay the deductible and we are running out of food,” Robin Butkus said. “And I still have bills to pay. The bills don’t go away because my husband died.”

Bailey Liipfert, the family’s attorney who represents many others with disabilities, says Max’s situation falls in an unfortunate loophole in the safety net intended to help children and adults with disabilities.

“People figure that... if you have no money, if you are severely disabled, there’s a safety net to catch you,” Liipfert said.

However, the family has only a couple options the way the law is written: they can move to a state that has a lower Medicaid deductible; or institutionalize Max, in which the government will pay for everything.

“For Max, going to a facility setting probably would be endangering his life,” Liipfert said.

Max’s mother says her child’s weak immune system and the fact that many medical facilities are unable to treat people with his type of syndrome means institutionalizing her son could be a death sentence.

“He lost his dad and now they say we have to institutionalize him?” Robin Butkus said. “It doesn’t make sense... to put him in an institution and say there is no more quality of life... That’s not right.”

Making Max a ward of the state is not an option for the Butkus family. Robin Butkus says she’s fought 16 years to give Max the best quality of life she can and she doesn’t plan to stop now.

“He gives value to our lives. He teaches us just to be thankful for everything you have every day,” Robin Butkus said.

Congress could step in and correct the loophole. New legislation has been discussed in committees, but the legislation hasn't moved in three years. State lawmakers could also help by lowering the state Medicaid deductible for those with disabilities. North Carolina has one of the highest deductible rates in the country.