Affordable Care Act decision has real implications for Taylorsville dad, daughter

By Marjorie Cortez, Deseret News
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TAYLORSVILLE — Shannon Millet says it’s just too stressful to follow every nuance of the constitutional challenge of the Affordable Care Act now before the U.S. Supreme Court.

The court’s ruling will have significant quality of life implications for her and her father, Dan Millet, who is her primary caregiver. Shannon Millet, 27, has a condition that most closely resembles congenital spinal muscular atrophy, which has resulted in muscle wasting and mobility impairment.

She requires a ventilator to breathe and a feeding pump for nutrition.

By requiring all Americans to carry insurance or pay a penalty, ACA seeks to create a large-enough insurance risk pool to bar insurance companies from refusing coverage to those with pre-existing medical conditions and limit how much they can charge older people. Opponents say the law falls outside the Constitution’s commerce clause.

"We hope people make the right decision about that. It’s all we can do," Shannon Millet said at her Taylorsville home Monday.

Presently, she is on Medicaid through a state waiver and is covered by the insurance provided by her father’s employer, a large corporation that manufactures health care equipment.

She requires nursing care 24/7 to ensure her trachea is clear of obstructions, that she is hydrated and fed, that she is kept clean and dry and that her body is regularly repositioned because she has too little muscle mass to move her 60-pound body on her own.
The Millets consider themselves "the lucky ones," Dan Millet says.

"We're ridiculously lucky," his daughter added.

The family knows all too well that their good fortune can turn on a moment. There was a time when Dan Millet carried more than $240,000 in debt from the cost of his daughter's care. Intermountain Healthcare eventually forgave the debt.

There was also a time when she was on a waiting list for Medicaid services. She spent a couple of years living in a nursing home, where the care was substandard, she said.

If Millet were to lose his job, it's unlikely he'd find another with the same level of benefits.

Now, with the help of nurses, Millet is able to oversee his daughter's care at home. "If I have a good night, he's maybe getting two or three hours (of sleep) a night," Shannon Millet said.

In recent years, Shannon Millet has been working toward a degree at Salt Lake Community College to become a social worker.

The passage of the Affordable Care Act has given her hope of a more independent future. After 2014, if the ACA's full effect is realized, she could conceivably qualify for her own insurance coverage through an employer.

"It means I could get a job and start to help out society, which is what I want to do because they have helped me out so much," she said.

Doctors told the family that she probably wouldn't live past the age of 7. That was 20 years ago.

Extending her life has meant many sacrifices for Millet, who has been a single father to Shannon and three other children since 1990, following a divorce.

As his other children have grown up and left home, he's been on his own to care for his daughter, whose medical care has cost his current employer some $3 million over the past decade.

"I say she's worth it," he said.

As the Supreme Court debates issues that could clearly impact...
their futures, the family "prays for the best," Dan Millet said.

"We hope we can keep our family together, that I can keep working and we can keep her safe."

**Since ACA's passage in March 2010:**

- 21,016 Utah Medicare recipients saved more than $12 million dollars on medicine
- 790,608 Utahns receive coverage of preventative services such as cancer screenings without co-payments or deductibles

- 1,183,000 Utahns no longer face a lifetime cap on their insurance benefits
- 21,247 more young adults up to age 26 in Utah are covered under their parents' insurance
- 696 Utahns are now covered through the pre-existing condition insurance plan

Source: Utah Health Policy Project

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