

PUBLIC COMMENTS

SB 50

HOUSE COMMITTEE ON HUMAN SERVICES

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Kyle Cox

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Thank you for the opportunity to testify today. My name is Kyle Cox, and I am a self-advocate testifying in support of SB 50. I grew up in El Paso, a 5th generation El Pasoan, and now reside in College Station.

I have Duchenne Muscular Dystrophy (DMD), the leading fatal genetic disorder among children. Boys with DMD generally lose the ability to walk between 8 and 12 years old and succumb to the disease in their late teens or early 20's. I stopped walking at age 12 and have used a wheelchair since then. I also have a bi-lateral hearing loss from injuries sustained at birth.

After several years waiting on the interest list, I have been on Medicaid waivers since 2006. I also receive Dependent Adult Child (DAC) benefits from Medicare now that my dad is receiving Medicare.

For much of my life I was told not to bother with college because getting a job would mean that I lose Medicaid or my waiver. Most boys with my disease play video games all day instead of attending college because they can't risk losing a waiver. Yet, I dreamed of attending Texas A&M since I was a toddler.

I ignored the advice of many and followed my dreams, earning a bachelor's degree from Texas A&M and then a Master's in Public Administration from the Bush School of Government and Public Service.

Now I'm faced with a choice between working or keeping my waiver. If I earn more than \$1,000 per month (after my Social Security check of \$1350), there is a 100% payback to Medicaid. My disease is progressive, and I will continue to decline. Even if I were healthy enough to risk losing the waiver today, I would be foolish to risk losing my waiver.

I and many others are faced with a binary choice: we can be a tax payer or a tax consumer. We cannot be both.

People with chronic illness who will always need Medicaid as a safety net, should have a path to becoming a taxpayer without the risk of losing Medicaid or their waiver. If we are forced to choose, we will always choose the safety net.

I am anxious to realize the benefit of all the years of education. I – like most every human being – gain fulfillment from working and being a productive member of society. I implore you to remove barriers and create incentives instead of disincentives to employment.