Dreaming Beyond Limits

By DeAnna Gaines

Courtney is a vibrant young woman with Down syndrome who has big dreams of becoming an actress. From the moment she first saw a stage, I've watched her light up with a passion and creativity that's impossible to ignore. As her mother and biggest cheerleader, I've always believed in her abilities and encouraged her to dream as big as her heart desires. But, despite her remarkable achievements, like starring as the lead in the short film *I Can Do All Things* and establishing her own brand - <u>Being Courtney</u>, there are barriers that I fear will prevent her from realizing her dream.

As we celebrate National Disability Employment Awareness Month (NDEAM), I want to shed light on a challenge that many people might not realize: the limitations of Supplemental Security Income (SSI). SSI is a program that provides essential financial support to individuals with disabilities, like Courtney, to help cover their basic needs. While it's a lifeline for many, there's a catch because she can only earn up to a certain amount each month without risking her SSI benefits.

For someone like Courtney, this creates a serious problem. In the unpredictable world of acting, where roles may be short-term and pay irregular, a single acting job could mean she earns too much in one month and then nothing the next. Even though her income might not be consistent, acting could push her over the income limit, leading to a reduction or loss of her benefits. Without SSI, Courtney could lose the financial stability she depends on to meet her basic needs each month.

Imagine having to choose between pursuing your dreams and losing the security of your monthly income—that's the position Courtney faces. And it's not just income limits; Courtney is also restricted from saving more than \$2,000 in her name. This means she can't even set aside money for emergencies or plan for the future without risking her benefits.

As a mother, it's hard to watch her face these barriers. I want her to chase her dreams and build a career, but I also worry about her long-term security, especially since I won't always be here to support her. Like many families in this position, we are forced to make difficult decisions that no one should have to make.

NDEAM is a time to reflect on the progress we've made in creating inclusive workplaces, but it's also a time to acknowledge the work that still needs to be done. To truly level the playing field, we need to update SSI policies to reflect the realities of today's cost of living and the evolving nature of work. Increasing asset and income limits would allow individuals with disabilities to build meaningful careers without the constant fear of losing their financial safety net.

This NDEAM, I'm calling for change. SSI needs to be updated, and an important step forward is supporting the <u>SSI Savings Penalty Elimination Act</u> (H.R. 5408/S. 2767). While this bill doesn't

address income limits, it's an important starting point. Let's take steps toward giving Courtney, and others with disabilities, the freedom to dream big, just like everyone else.