

My Sister has Down Syndrome and is Encouraged Not to Work

By Damon Kruppa

My name is Damon Kruppa, and I am a 22-year-old recent college graduate. My sister, Mia, is 19 years old and has Down syndrome. Despite her disability, Mia is driven to achieve her goals. She is attending Salem State University this fall, works at a café, has a boyfriend, and strives to be as independent as possible. However, outdated laws are forcing her to make difficult choices that prevent her from fully participating in the workforce and achieving financial stability.

Programs like Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were designed to help individuals with work-limiting disabilities meet their basic needs. However, the rules governing these programs often discourage individuals like Mia from working more hours or earning more money.

If she has more than \$2,000 in savings, she risks losing her benefits altogether. While there are work incentives for people who receive SSI and SSDI such as the Student Earned Income Exclusion, 1619(b) and ABLE accounts - they are complicated, difficult to navigate, and still very minimal. For each dollar my sister earns at work, she loses 50 cents of her SSI. It's a choice between financial stability and personal fulfillment — a choice no one should have to make. The system, as it stands, discourages people like Mia from working more, saving money, and contributing more fully to society.

This is not just about Mia; it's about the many people with disabilities who want to work but are held back by policies that penalize them for doing so. Mia and I recently went to Capitol Hill with the National Down Syndrome Society to advocate for The SSI Savings Penalty Elimination Act. The SSI Savings Penalty Elimination Act would increase asset limits to \$10,000 for individuals and \$20,000 for married couples eliminating the marriage bias. It would also index both limits annually to adjust for inflation. Our current system tries to apply a “one size fits all” approach, but it's clear that it's failing to meet the diverse needs of the disability community. This would be a fantastic first step for change – something that hasn't happened in over 35 years!

Contact your members of Congress and ask them to support The SSI Savings Penalty Elimination Act. It's time for a change. People with disabilities deserve the opportunity to work as much as they can and want and still receive the support they need. Reforming SSI and SSDI to allow for more income and savings would empower people like Mia to achieve their full potential without fear of losing the benefits they rely on.