Why Disability Doesn't Work if You Work, With Advanced Illness

Financial toxicity is also about the systemic designs of our assistance programs, which are poorly equipped to meet the needs of the seriously ill.

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The word "financial toxicity" is often used in the context of cancer care. Why is that? Here is my experience with financial instability.

I became eligible for disability shortly after diagnosis with glioblastoma. This diagnosis qualifies for the Social Security Administration's list of compassionate allowance conditions, which "are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits." These "conditions" facilitate expedited approval for Social Security Disability benefits. However, my claim as adjudicated by the administration deemed me to be "temporarily disabled." I am subject to a three-year monitoring period prior to being determined "totally and permanently disabled." This distinction is important because under temporarily disabled status, my disability benefits do not qualify as income. Without this qualification, my benefits, approximately 60% of my salary at time of disability, do not have bearing on our family's income-to-debt ratio. Inability to qualify for a mortgage is, to date, the most detrimental impact to our family. We rent a home and pay a premium for our financial insecurity, strange as that sounds. We expend two hundred to three hundred dollars more monthly than a mortgage for a comparable home.

What's more, my earnings are "capped": should I exceed a threshold of monthly earnings, my disability "cuts back." That is to say, there is little incentive for me to earn income beyond this threshold, set at federal poverty level. To further complicate finances, my publicly held student loan debt is dismissed after this three-year monitoring period, but again, should I exceed earnings beyond the annual FPL "cap," I disqualify my eligibility for dismissal.

To put things plainly, if I work to my current full potential I "break even," contrasting my increased earnings with cut back disability benefit disbursement. There is little incentive for me to earn more, unless I might earn so much that I exceed my disbursement. Earning more harms rather than helps my family. In this sense, I am disincentivized to work. It is better off for me to remain at federal poverty level. Counterintuitive.

The fundamental problem is this. Disability benefits, programmatically, are not designed to aid

those with progressive advanced illness. True, my family required disability assistance in the months following surgery. We simply could not have lived otherwise. I was completely unable to work, suffering from the most severe of my symptoms: significant motor impairment, frequent seizures, daily headaches, daily nausea, and significant fatigue. Given the nature of my neurological deficits, during my two plus years of survivorship I have learned to mitigate symptoms through rehabilitative therapy, proactive planning, and completing my first “phase” of active treatment. I am now “recovered” enough to return to work, as I have. This recovery, though, is short-lived. Glioblastoma is a recurrent disease, and at the time of recurrence the survival median shrinks significantly. I am currently at my most “able” to work.

Contrast my case with others who may become disabled. Imagine an incident: work-related, vehicle crash, unforeseen accident, and so forth, these folks present with most acute trauma in the near-term and recover slowly to return to the workforce. The Social Security Trial Work Program incentivizes people to return slowly to work by suspending medical review, protecting disability disbursement during a trial work period, regardless of the income earned, with the ultimate goal of terminating disbursements after the conclusion of a trial work period. The candidate for this program is the person who is disabled today and is predicted to be able to work in the future. Here the income caps make sense, almost by default, because one may not be expected to reach full earnings potential while returning to work.

This is not my case.

My greatest earnings potential is now. Though physically and intellectually unable to maintain a full-time work schedule, I am able to sustain the part-time, from-home hours as I have been, thanks to my generous and caring employer. A recent work project has demanded full use of resources from the assigned team, including me. This is a great opportunity to invest maximum hours while the work is available and pressing. Though, should I gather the energy to support in the short term to drive the project toward completion, I risk cutting back benefit disbursements and putting my publicly-held loan dismissal at risk.

Rather than near-term disability, with the aim to return to work, as SSD benefits and Trial to Work programs are designed, my part-time work capacity is greatest now, and cannot be counted on for more than a few months, given the nature of my progressive advanced illness.

Financial toxicity, a buzzword in cancer care and survivorship, is not only the rising cost of treatment and prescription drugs, the inability to work full-time, or the loss of care partner income, such as a spouse who reduces hours to respond to increased care needs, it is also, or maybe it is more, about the systemic designs of our assistance programs which are poorly equipped to meet the needs of the seriously ill.

When my monitoring period is up after three years from the date of disability, there is only a chance I’ll still be alive to be monitored: the median survival time for glioblastoma with my particular genetic profile is 27 to 31 months.

I will likely die in the home that our family does not even own. This is the damned if you do,

damned if you don’t scenario: work more, earn less; earn less, earn less. That is financial toxicity.

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