

**Childhood Cancer Survivors and Social Security Benefit Coverage: A Report from the Childhood Cancer Survivor Study (CCSS)**

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**Background:** Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are the federal programs that provide disability benefits. SSI is for those with limited income and is not based on prior work history. SSDI pays benefits to individuals who worked and paid Social Security taxes. The high level of unemployment among childhood cancer survivors suggests that many may receive these benefits. We evaluated a subset of survivors and siblings, within the CCSS cohort, to determine prevalence of SSI and SSDI coverage and experiences with coverage denial.

**Methods:** A random sample of survivors (N=698) and siblings (N=210) ages  $\geq 22$ , evenly selected from age strata (18-30, 30-39, 40+), completed a health insurance survey between March 2011-March 2012. Using multivariable generalized linear models to generate relative risks (RR) and 95% confidence intervals (95% CI), we determined whether survivors were more likely to have ever been covered by SSI or SSDI. Models accounted for familial correlation, and were adjusted for gender, age and race.

**Results:** Mean age was similar for survivors (37.3, sd=8.2) and siblings (37.8, sd=9.6;  $p=0.44$ ). Gender and race did not differ. The most common diagnoses were leukemia (37%) and central nervous system (CNS) malignancy (15%). Survivors reported having received SSI (14.6%) and SSDI (9.8%) more often than siblings (2.5%,  $p<0.001$  and 4.8%,  $p=0.03$ , respectively), yet had also been denied SSI (8.2%) and SSDI (6.8%) more often than siblings (<1% each;  $p$ 's<0.001). In multivariable analyses, survivors were more likely to ever have SSI (RR 5.74, 95% CI 2.37-13.94) and SSDI (RR 1.96, 95% CI 1.03-3.74) compared to siblings. Survivors of CNS malignancy (RR 6.13, 95% CI 3.35-11.22), bone cancer (RR 5.38, 95% CI 2.53-11.43), and leukemia (RR 2.69, 95% CI 1.46-9.95) faced elevated risks of ever having either SSI or SSDI coverage compared to siblings.

**Conclusions:** Childhood cancer survivors receive SSI and SSDI more often than siblings but are also more likely to experience denial. These programs may play an important role in easing survivors' financial burden, but further research is required to assess the longitudinal impact on survivors.