

# LONGITUDINAL PATTERNS OF DISABILITY PROGRAM PARTICIPATION AND MORTALITY ACROSS CHILDHOOD SSI AWARD COHORTS

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*We follow six cohorts of childhood Supplemental Security Income (SSI) disability awardees for a time horizon up to 30 years, using program records on demographics, type of impairment, SSI and Disability Insurance (DI) reciprocity, and mortality. We use descriptive analysis and multinomial logit regression for repeated cross-sections of the six award cohorts, controlling for years since first award. For all award cohorts, many individuals transition from SSI reciprocity to DI or nonbeneficiary status. Others die over time. Accounting for DI program participation is necessary to obtain a full picture of disability program participation in adulthood. SSI-only reciprocity substantially diminishes in adulthood. However, DI involvement increases. An increasing proportion of individuals receives both benefit types (SSI and DI) as the cohorts age in adulthood. The trajectories of outcomes across successive award cohorts change in important ways. First, we observe a strong trend of increased transitions to nonbeneficiary status among survivors as we move from early award cohorts to later cohorts, with a sharp upward shift around the time of welfare reform in the mid-1990s. Second, the data show a secular decline in mortality across award cohorts. The data suggest that a substantial portion, but not all, of that decline has been affected by the Supreme Court's *Zebley* decision. Increased incidence of transitions to nonbeneficiary status and reduced mortality across award cohorts have opposing effects on the duration of disability benefit receipt.*

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## Introduction

The Supplemental Security Income (SSI) program provides cash assistance to people with low income and limited resources who are aged 65 or older, blind, or disabled. Children younger than age 18 and young adults with severe disabilities can qualify if they meet SSA's definition of disability and if they financially qualify based on the SSI income and resources screens. These children and young adults face challenges, including severe health problems, disabilities, and being raised in a family environment of economic hardship. A growing body of empirical literature demonstrates that severe health problems and disabilities in childhood have profound effects on adult outcomes (Emerson and others 2014; Currie 2008b; Smith 2005, 2007). Likewise, growing up in families

affected by poverty results in a variety of challenges in adulthood (Currie 2008a; Newachek and others 1998). Thus, understanding longitudinal patterns of disability program participation of childhood SSI awardees into adulthood is important in assessing the role of the SSI program in addressing the life-cycle challenges facing

### Selected Abbreviations

CDR	continuing disability review
DI	Disability Insurance
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act
SSA	Social Security Administration
SSI	Supplemental Security Income

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this important target group of the Social Security Administration's (SSA's) cash assistance programs.

Rupp and others (2005/2006) highlighted the importance of the SSI program in providing payments to families of youths with disabilities. For example, the authors showed that about 45 percent of childhood SSI recipients lived in a household where the parents or the guardians did not have earnings. Additionally, Bailey and Hemmeter (2014) showed that about 60 percent of child recipients lived in households receiving Supplemental Nutrition Assistance Program (SNAP) benefits. Further, they found that if the child's SSI benefit was not included as income, 58 percent of childhood SSI recipients would be living in poverty, compared with 32 percent when the SSI benefit was included in the calculation of income.

Because SSA's disability programs target people with severe disabilities, it is not surprising that lifetime duration on the SSI rolls historically has been high, especially when compared with the duration on other means-tested program rolls, such as the Food Stamp program (now SNAP) and Aid to Families with Dependent Children (AFDC)—now Temporary Assistance for Needy Families (TANF). Rupp and Scott (1995) estimated that childhood SSI awardees average 27 years on the rolls during the preretirement ages. Davies, Rupp, and Wittenburg (2009), using more recent data, confirmed the importance of SSI receipt in adulthood among childhood awardees. Thus, in order to assess the role of SSI in the lives of affected children and young adults, the receipt of cash benefits and other outcomes in adulthood should be considered. In this article, we attempt to fill some of the substantial gap in knowledge about the long-term disability program participation of childhood SSI award cohorts spanning up to 30 years—well into adulthood.

From a policy perspective, long duration on SSI is not inherently good or bad. For some childhood SSI awardees, long-term cash assistance is necessary for financial security. Premature discontinuation of benefits for this vulnerable group would be contrary to the objectives of SSI as a safety net program. In other cases, recipients may recover over time and return to nonreciprocity status coupled with successful entry or reentry into the labor force on a sustained basis, resulting in improved financial security and quality of life.

The changes in eligibility requirements and the fiscal impacts of childhood SSI benefit receipt have been widely discussed in the literature (for example, Rupp and Stapleton (1998); Rupp and Scott (1998); Burkhauser and Daly (2011); General Accounting Office

(1995, 1994); Government Accountability Office (2011); Kubik (2003, 1999); and Schwamm (1996)), but trends in duration of disability benefit receipt covering a time span before and after major legislative changes have received less attention. Major changes in legislation have substantially affected trends in both the characteristics of childhood awardees and exit patterns. Thus, it is paramount to consider the role of various major legislative and regulatory changes in affecting long-term outcomes. Because children are not supposed to work, but are expected to perform other important life activities according to prevailing social norms—such as successfully participating in the education system—it is not surprising that the SSI program as it applies to children has gone through major legislative and regulatory changes.

From 1974 to 1990, children were allowed SSI benefits only if they had a medically determinable physical or mental impairment of comparable severity to that required for adults (Public Law (PL) 92-603). Before 1990, the core of the disability screen for nonworking children was the Listing of Impairments. The focus of the test was to distinguish whether or not a child had a condition that met or medically equaled the Listing of Impairments for adults or a supplemental set of Listings of Impairments for children. Two important modifications in 1990 resulted in the dramatic expansion of the childhood SSI program. First, SSA modified the section of the Listing of Impairments dealing with childhood mental disorders, moving toward a more functionally based assessment of a child's categorical eligibility. Second, the 1990 Supreme Court decision on *Sullivan v. Zebley* resulted in a more fundamental change. As stated by Erkulwater (2006), the ruling began as a little-noticed denial of benefits, and then *Sullivan v. Zebley* evolved into a major class action lawsuit, representing more than 300,000 children. Because of *Sullivan v. Zebley*, the programmatic definition of disability for children was broadened, and it introduced individual functional assessments (IFAs) to determine SSI eligibility for some children. Together, these developments served to relax the definition of childhood disability somewhat.

The increase in the childhood SSI caseload following *Sullivan v. Zebley* led Congress to pass the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 (PL 104-193, or welfare reform), which eliminated the IFA (although the act retained functional evaluations for children), eliminated "maladaptive behaviors" from the Listing of Impairments, and required continuing disability

reviews (CDRs) every 3 years for children who were expected to medically improve. Importantly for our study, the PRWORA also required the redetermination of categorical eligibility after the child's 18<sup>th</sup> birthday, based on the adult disability criteria. Rogowski and others (2002) estimated that about 100,000 (42 percent) of the children who underwent the initial post-PRWORA CDRs mandated for those expected to medically improve had their benefits ceased. An additional 28,000 (45 percent) of the first round of youths undergoing an age-18 redetermination lost benefits. Awards dropped following these tightening measures, but quickly began to increase again.

In this article, we focus on trends in program participation among childhood SSI award cohorts from 1980 to 2000 for up to 30 follow-up years and assess the role of various factors affecting those trends. Davies, Rupp, and Wittenburg (2009) provided a foundation for our analysis. Those authors focused on comparing trends in SSI participation among the 1980 and 1997 cohorts of childhood awardees, and they concluded that there was some evidence of reduced duration in program participation for the 1997 cohort compared with the 1980 cohort of awardees. However, their study did not include data on transitions from the SSI program to the Disability Insurance (DI) program<sup>1</sup> or on concurrent SSI and DI benefit reciprocity. That study also did not separate surviving nonparticipants from those persons who died, nor did it include a systematic analysis of factors affecting differences in outcomes across award cohorts.

To our knowledge, there has been little research on the connection between SSI and DI in the context of the eventual possibility of childhood SSI awardees transitioning to the DI program during adulthood.<sup>2</sup> Burkhauser and Daly (2010) and Armour and others (2011) highlighted the fact that the structure of the DI benefit has been increasingly generous relative to SSI, providing a stronger incentive for recent award cohorts of children to acquire DI-insured status. Therefore, duration on the SSI rolls may decrease as young adults work long enough to qualify for DI, but overall disability program participation may not decline by as much, or may even increase because of differences in the way nondisability eligibility rules affect the probability of exits from the DI and SSI programs.<sup>3</sup> Recent research on SSA's Youth Transition Demonstration (Bucks Camacho and Hemmeter 2013; Hemmeter 2014) and the Marriott Foundation for People with Disabilities Bridges program (Hemmeter and others 2015) showed that, at least for the voluntary

participants targeted by those programs, a substantial proportion of young SSI recipients had transitioned into the DI program.

This article advances that recent research in several policy-relevant ways. First, rather than focusing on SSI only, we look at disability program participation in a more comprehensive way, by considering adult participation of childhood awardees in both the SSI and DI programs. This allows policymakers to obtain a better understanding of the way SSA's disability programs enhance financial security during the working-age portion of the life cycle. Second, the SSI program has changed substantially since its inception, and in this study, we assess how trajectories of program participation and exits that were due to death and other factors have changed over time, thus providing a useful starting point from which to study changes in future program participation. Third, we estimate individual-level models, controlling for various determinants of differences in trajectories across award cohorts, which allows us to assess the role of changes in selected awardee characteristics and other factors affecting outcomes. A greater understanding of factors affecting outcomes for various award cohorts could contribute to refinement of projections of program growth, might improve the understanding of the role of policy in shaping those outcomes, and should provide useful data on the reliance on disability benefits among childhood awardees as they age into adulthood. In this article, we do not judge program changes, but rather provide a description of the consequences of those changes.

This study also provides a foundation for future research on the ways in which the disability benefits and work activity of beneficiaries and former beneficiaries combine to enhance the financial security of childhood awardees in adulthood.

## **Research Objectives**

Our research focuses on two fundamental issues. First, we are interested in providing a refined picture of individual outcomes over various time horizons well into adulthood among childhood SSI awardees. The outcomes of interest include the following mutually exclusive categories: SSI only, DI only, concurrent SSI/DI status, off the disability rolls and alive, or deceased. For some analyses, we collapse the groups into broader categories (on the disability rolls, off the disability rolls and alive, or deceased).<sup>4</sup>

Second, we are interested in assessing the presence and nature of differences in program-status

trajectories across multiple award cohorts (1980, 1985, 1990, 1995, 1997, and 2000). Specifically, we question whether the reliance on disability benefits increases or decreases across the cohorts over the period under study. We look at outcomes for time horizons up to 30 years after first award, a time frame that allows us to examine adult outcomes for almost all of the childhood awardees in our sample. We also explain the differences in longer-term outcomes across award cohorts (which are profound, as shown in the next section), controlling for observable awardee characteristics (specifically—age, sex, and type of impairment). We attempt to discern whether the raw differences in outcomes across award cohorts are explained by the mix of awardees as represented by our independent variables and to what extent those differences are attributable to other unmeasured differences associated with award cohort and calendar year of the given outcome.

Our fundamental goal is to provide a better understanding of how policies affect outcomes. In particular, SSI-to-DI transitions are relevant for several reasons. First, access to DI enhances financial well-being in several ways. DI benefits can be substantially higher than SSI benefits; in 2013, the average monthly DI benefit for workers was \$1,130, compared with a maximum federal SSI benefit of \$710.<sup>5</sup> DI beneficiaries with earnings up to the substantial gainful activity (SGA) level can continue to receive benefits without any reduction. During a 9-month initial trial work period, even earnings above the SGA level do not affect benefit receipt and monthly amount. Second, DI benefits, after a 24-month waiting period,<sup>6</sup> are supplemented by Medicare coverage, which provides a different bundle of health care services than does Medicaid coverage (for which most SSI recipients are automatically eligible for). The Medicare waiting period is waived under certain circumstances. Medicare coverage may continue for many years after the cessation of disability cash benefits for work-related reasons.<sup>7</sup> Concurrent beneficiaries are eligible for both Medicare and Medicaid, which provides better health care coverage than either source alone.

Policies may affect outcomes through the characteristics of applicants who are awarded benefits under the allowance policy regime that is applicable at the time of the award and through policies affecting exits between the time of award and the outcome year of interest. For example, the case mix of awardees can affect outcomes for several reasons. Awardees with

impairments with higher mortality risk are more likely to die and thus less likely to stay on the SSI rolls, transition to concurrent or DI-only status, or transition off the rolls while alive. Awardees with impairments with lower mortality risk may be more likely to medically recover or to successfully transition from school to work as adults, and therefore they may be more likely to transition to DI-only or concurrent benefit status or exit the rolls (while alive). Thus, outcomes even many years after initial award can be profoundly affected by policies that affect the characteristics of awardees and policies implemented between the time of initial award and the relevant follow-up observation point. The award cohorts that are separated by substantive changes in the definition of disability, such as those in the early 1990s, are especially likely to experience different outcomes.

Clearly, awardee characteristics and conditions at the time of award do not provide the whole story. Temporary or longer-term exits from disability beneficiary status are also affected by policies and implementation practices at the time of the follow-up observation point. The extent and targeting of CDRs at follow up; program changes, such as the introduction of the Ticket to Work program (which occurred many years after award for some members of our analysis sample); and the Great Recession (which resulted in diminished employment opportunities) all may affect outcomes among survivors, regardless of the situation at the time of initial award.

Policies directly affecting trends in participation may include those associated with CDRs, age-18 redeterminations, and employment support initiatives. A variety of other factors—such as changes in medical technology that affect mortality trends in general and labor market trends that affect transitions to nonbeneficiary status—may also affect outcomes. Unfortunately, we cannot directly control for the effect of all policy changes on shifts in trajectories over award cohorts. Our analysis is limited to indirect evidence of policy effects. Thus, inferences about policy effects are to be tempered given these limitations.

## **Data and Methods**

We derive our data from administrative/program records maintained by SSA. First, we use the Supplemental Security Record (SSR)—SSA's record system for the SSI program—to identify cohorts of children aged 0 to 17 who were first awarded SSI benefits in 1980, 1985, 1990, 1995, 1997, and 2000 and obtain their SSI benefit eligibility status. We derive other

characteristics, such as sex and type of impairment at the time of award, from the SSR. We then track those awardees' benefit eligibility and mortality status for various time horizons up to 30 years after award, constrained by the last observation point at the time the data were originally extracted, which was in 2010. The Master Beneficiary Record—SSA's record system for the DI program—provides information on receipt of DI benefits. The Numident—a file that includes the Death Master File—provides date of death.

We conduct descriptive analyses of SSI, DI, and mortality outcomes for our sample population using various time horizons and then conduct multinomial logit analyses of the same outcomes, using award cohort, sex, age at award, and broadly defined impairment types as independent variables. We use seven impairment types at award in this analysis:

- intellectual disabilities and other mental impairments;
- neoplasms;
- congenital anomalies;
- diseases of the nervous and sensory systems;
- diseases of the respiratory system;
- other identified diagnoses; and
- all other and unknown diagnoses.<sup>8</sup>

The multinomial logit framework allows us to look at differences across award cohorts in the relative probability of each outcome, holding constant the age, sex, and diagnostic composition of each cohort.

Our time horizon allows us to observe some awardees well into adulthood. For example, for youths who were first awarded SSI benefits at age 17 in 1980, 1985, or 1990, we observe program and mortality outcomes from ages 37 to 48. That provides sufficient time for some of those individuals to have worked (if they were able), earned entitlement to DI benefits, and converted to DI-only or concurrent SSI/DI benefit status through the middle of their working-age adult life cycles. Other awardees were young adults at the end of our observation window (for example, individuals aged 10 at award in 1995 were aged 25 in 2010). Some awardees still were children (for example, individuals aged 5 at award in 2000 were aged 15 in 2010). Nonetheless, even for the 2000 award cohort, we observe program transitions and mortality over a 10-year period. For the 1980, 1985 and 1990 award cohorts, we observe adult outcomes even for the youngest of childhood awardees.

Before looking at the long-term outcomes, we present the characteristics of SSI children by year of award. Over time, there have been substantial changes in the characteristics of childhood SSI awardees (Table 1). There was a general increase in the proportion of male awardees that is reasonably consistent across award cohorts. There was also a decline in the proportion of older childhood awardees between 1980 and 2010 and some evidence of reduced average and median age across award cohorts. Between 1985 and 1995, there was a substantial increase in the proportion of awardees with any mental impairment (including both intellectual disabilities and other mental impairments), followed by a 10 percentage point drop between 1995 and 1997, and an upward trend surpassing the 1995 high in 2010.<sup>9</sup>

The statistics by type of mental impairment, while striking, are more difficult to interpret because of secular shifts in diagnostic labeling (for example, from *mental retardation* to *intellectual disabilities*) and in the use of psychiatric labels (for example, *autism spectrum disorders*—Shattuck (2006)). Additionally, when an individual has more than one disabling condition, the disability decision process only records up to two disabilities in our data, one of which is designated as primary and the other as secondary. Because these designations are left to the disability examiner, and we use only the primary disability diagnosis, there may be differences in how disabilities are recorded in the data. Although there is clear evidence of a reduction in the proportion of awardees with physical disabilities in 1995 and later, compared with earlier award-cohort years, that picture is somewhat clouded by fluctuations in the “other/unknown” diagnostic category. Nevertheless, when all nonmental disabilities are combined, there is still a net overall increase over time in the more inclusive “all mental impairments” category, which includes both intellectual disabilities and other mental impairments. We return to the potential role of changes in cohort characteristics in the long-term outcomes of childhood SSI awardees later in the study.

## Results

Our focus in this article is on trends in annual award-cohort trajectories. This subject involves complex patterns, as childhood awardees experience events occurring during the remainder of their childhoods and in their working-age adult life cycles. We first present long-term outcomes for members of the 1980 award cohort up to age 48, to gauge the potential importance of our data and our research questions.

**Table 1.**  
**Characteristics of children awarded SSI benefits, by award cohort**

Characteristic	1980		1985		1990		1995		1997		2000		2010	
	Estimate	Standard error												
Sex (%)														
Male	57.06	0.23	58.29	0.23	60.69	0.18	63.81	0.12	61.45	0.14	63.25	0.13	65.08	--
Female	42.94	0.23	41.72	0.23	39.31	0.18	36.19	0.12	38.55	0.14	36.76	0.13	34.92	--
Age (%)														
0–5	36.74	0.23	45.38	0.23	43.32	0.18	44.90	0.12	52.54	0.15	48.47	0.13	42.03	--
6–12	34.10	0.22	31.10	0.22	35.51	0.17	36.38	0.12	32.02	0.14	36.13	0.13	42.00	--
13–17	29.16	0.22	23.53	0.20	21.18	0.15	18.72	0.09	15.44	0.11	15.40	0.10	15.97	--
Average age (years)	8.31	0.03	7.23	0.03	7.25	0.02	6.84	0.01	5.98	0.02	6.28	0.01	--	--
Median age (years)	8.00	...	6.00	...	7.00	...	6.00	...	5.00	...	6.00	...	--	--
Diagnosis (%)														
All mental impairments	---	---	47.27	0.24	54.98	0.18	64.21	0.12	54.09	0.15	59.72	0.13	66.06	--
Intellectual disabilities <sup>a</sup>	---	---	40.24	0.23	40.99	0.18	30.87	0.11	25.94	0.13	19.11	0.10	7.81	--
Other mental impairments	---	---	7.03	0.12	13.99	0.13	33.34	0.11	28.16	0.13	40.61	0.13	58.26	--
Neoplasms	---	---	4.08	0.09	2.85	0.06	1.73	0.03	2.16	0.04	1.89	0.04	1.65	--
Nervous system	---	---	20.51	0.19	18.06	0.14	7.90	0.07	8.99	0.08	7.69	0.07	6.23	--
Respiratory system	---	---	2.41	0.07	2.47	0.06	2.59	0.04	3.38	0.05	3.14	0.05	2.11	--
Congenital anomalies	---	---	9.41	0.14	4.48	0.08	3.99	0.05	5.19	0.07	4.78	0.06	4.50	--
Other identified diagnoses	---	---	8.95	0.13	9.08	0.10	4.81	0.05	6.00	0.07	5.23	0.06	5.45	--
Other/unknown	---	---	7.36	0.12	8.09	0.10	14.77	0.09	20.19	0.12	17.56	0.10	13.99	--
N	44,533		45,117		76,453		173,559		116,187		144,068		204,219	

SOURCES: Authors' calculations using SSA administrative records and the *SSI Annual Statistical Report, 2010* (SSA 2011).

NOTES: Diagnostic codes are unreliable before 1983.

SSA = Social Security Administration; SSI = Supplemental Security Income; . . . = not applicable; -- = data not available; --- = data not included.

a. Formerly referred to as mental retardation.

Our first research question focuses on the empirical importance of providing more detail than the simple “on SSI” versus “not on SSI” comparison used in recent work. The second research question provides an overview of gross disability program participation rates over award cohorts, accounting for both SSI and DI in adulthood by time elapsed since first award. The remaining research questions focus on mortality—third question; exits to nonbeneficiary status—fourth question; and receipt of benefits (SSI, DI, or both) among surviving disability program participants in adulthood—fifth question. The latter includes the contribution of disabled-worker and auxiliary benefits in adulthood.

***Research Question 1: What is the Empirical Relevance of Including Information on DI-Only Status and Death Outcomes in Adulthood, Versus Exclusively Focusing on SSI-Only Status?***

A useful way to explore this issue is to illustrate the experience of two different cohorts of awardees. Charts 1 and 2 summarize the programmatic and mortality experience of the 1980 and 2000 award cohorts of youths aged 17 at the time of award. We focus on those particular groups because they allow us to track the youths relatively late into adulthood for the earliest and latest award years in our analyses; other age-at-award and year-of-award cohorts have different trajectories. Consistent with Davies, Rupp and Wittenburg (2009), who focused on the trajectory of SSI receipt in adulthood, we find considerable decline in the proportion on the SSI rolls up to the end points of our observation period.

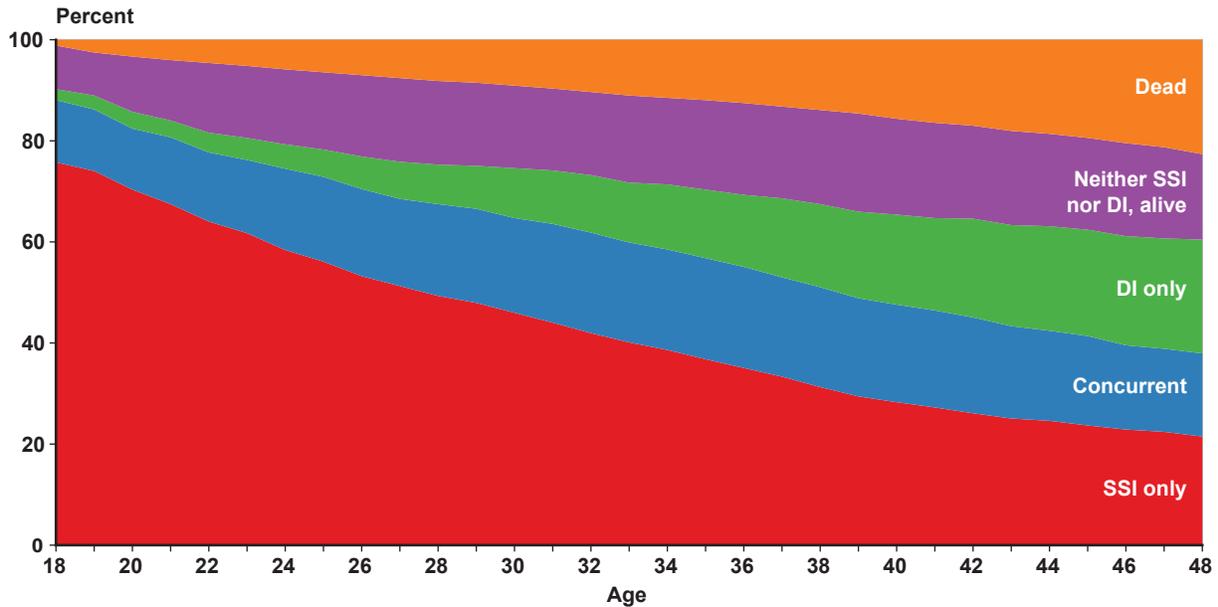
When we consider transitions to DI and concurrent SSI/DI benefit-receipt status, a considerably more refined picture emerges, which provides a more realistic view of transitioning off the SSI rolls. Access to DI records allows us to observe transitioning to DI-only status, which means that the former SSI recipient is not simply “off SSI,” but continues to receive public disability benefits, albeit in the form of social insurance rather than welfare. For the 1980 cohort, over half of awardees were no longer on SSI at age 48 (Chart 1); but we also observe that a slightly higher proportion received DI benefits (39 percent) compared with those who received SSI benefits (38 percent). There is an overlap between these two categories because some awardees (16 percent of the total) received both types of benefits. This reflects the fact that some former SSI recipients “earned” social insurance benefits, but still

continued to need supplementary cash payments from the SSI program.<sup>10</sup> In fact, about 60 percent received some form of disability benefits at age 48, most of them receiving DI. Only 21 percent of all awardees received SSI-only benefits. A substantial minority (40 percent) no longer received any disability benefits. Seventeen percent were off the rolls and alive, and 23 percent died by age 48. For the 2000 cohort, even over an abbreviated period, we see a substantial change in rates of mortality and program participation (Chart 2). At age 28, only 6 percent had died (relative to 8 percent of the 1980 cohort). More strikingly, for the 1980 cohort, only 17 percent were receiving neither SSI nor DI (and alive) at age 28; for the 2000 cohort, over 30 percent were receiving neither SSI nor DI (and alive) at age 28.

The data also show that death is an important outcome affecting duration on the disability rolls, especially when we consider program participation over longer segments of the life cycle. We find that although the rate of exit because of death is relatively small during the first year or two, attrition because of death becomes much more important throughout adulthood. This supports the notion that the SSA disability determination process is successful in identifying a severely disabled segment of awardees. Although the statutory definition of disability explicitly refers to medical conditions that are expected to result in death, the interesting finding here is that attrition because of death becomes important many years after initial award. This suggests that chronic conditions that are not predictably life threatening nevertheless may result in the shortening of the life span of a nontrivial portion of awardees. Individuals who die may experience financial hardship and high medical expenses during the years prior to death. Although Charts 1 and 2 provide useful illustrations that highlight the importance of considering transitions from SSI to DI and from SSI to concurrent (SSI/DI) status, to surviving non-participant status, and death, they reflect only two of our award cohorts (1980 and 2000) and are limited to childhood awardees 17 years of age at award. Table 2 provides a more comprehensive picture, by presenting detailed outcomes for all six of our award cohorts at various points from 1 to 30 years after first award. For all award cohorts, we observe outcomes for 10 years after award; available information for longer time horizons is sparser because of right-censoring of the data.

We highlight two salient observations. First, accounting for DI participation is important because it raises the observed rate of participation in either or

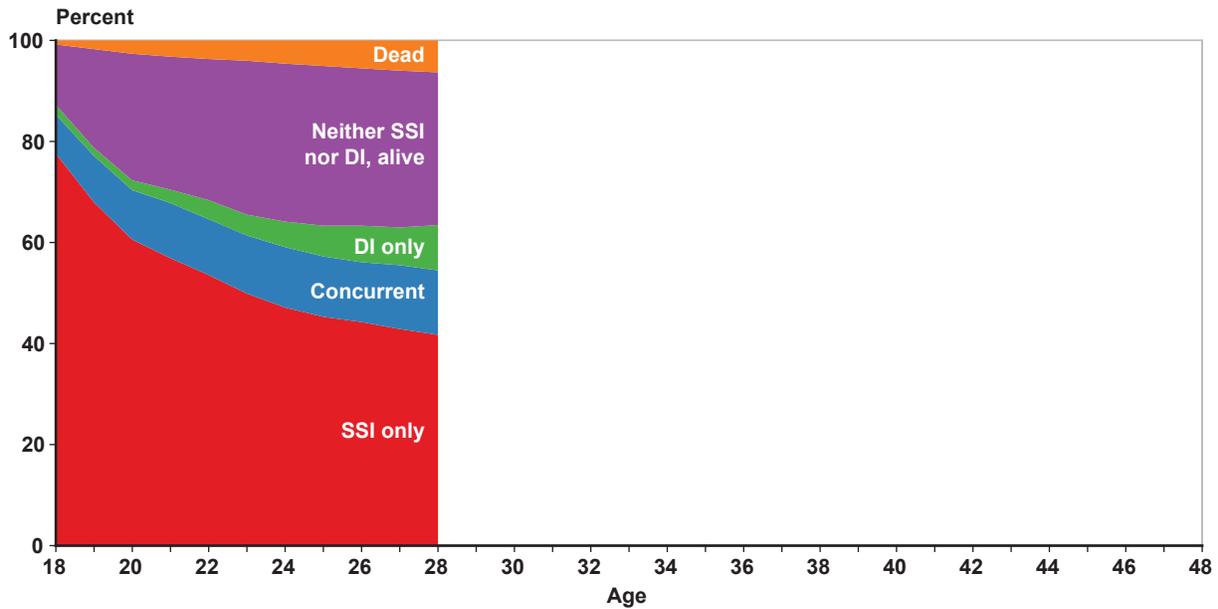
**Chart 1.**  
**SSI and/or DI program participation and mortality experience of the 1980 cohort of SSI childhood awardees aged 17 at award**



SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

**Chart 2.**  
**SSI and/or DI program participation and mortality experience of the 2000 cohort of SSI childhood awardees aged 17 at award**



SOURCE: Authors' calculations using SSA administrative records.

NOTES: Data for ages older than 28 are not shown because those ages are reached beyond the last observation point for the 2000 awardee cohort at the time the data were originally extracted (2010).

DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

**Table 2.**

**SSI and/or DI program participation and mortality experience of SSI children aged 0–17 at award, by award cohort and years after initial award: Percentage distribution of awardees by outcome**

Award cohort	SSI only		DI only		Concurrent (SSI/DI)		Any disability benefit (subtotal)		Neither SSI nor DI, alive		Dead		N
	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	
<b>1 year after award</b>													
1980	80.73	0.19	0.17	0.02	0.85	0.04	81.76	0.18	15.10	0.17	3.14	0.08	44,533
1985	82.58	0.18	0.06	0.01	0.55	0.03	83.20	0.18	13.71	0.16	3.09	0.08	45,117
1990	86.11	0.13	0.06	0.01	0.48	0.02	86.65	0.12	10.85	0.11	2.50	0.06	76,453
1995	85.71	0.08	0.03	0.00	0.23	0.01	85.97	0.08	12.45	0.08	1.59	0.03	173,559
1997	82.73	0.11	0.03	0.01	0.20	0.01	82.96	0.11	15.09	0.11	1.95	0.04	116,187
2000	84.58	0.10	0.03	0.00	0.21	0.01	84.83	0.09	13.52	0.09	1.65	0.03	144,068
<b>5 years after award</b>													
1980	64.62	0.23	0.90	0.04	2.82	0.08	68.34	0.22	25.09	0.21	6.57	0.12	44,533
1985	67.30	0.22	0.68	0.04	2.36	0.07	70.34	0.22	22.78	0.20	6.88	0.12	45,117
1990	76.71	0.15	0.45	0.02	2.05	0.05	79.21	0.15	15.63	0.13	5.16	0.08	76,453
1995	51.75	0.12	0.38	0.01	1.24	0.03	53.38	0.12	43.82	0.12	2.81	0.04	173,559
1997	54.30	0.15	0.42	0.02	1.11	0.03	55.83	0.15	40.71	0.14	3.46	0.05	116,187
2000	59.86	0.13	0.34	0.02	1.06	0.03	61.26	0.13	35.81	0.13	2.92	0.04	144,068
<b>10 years after award</b>													
1980	56.14	0.24	2.45	0.07	6.64	0.12	65.23	0.23	25.41	0.21	9.35	0.14	44,533
1985	60.59	0.23	1.98	0.07	5.86	0.11	68.43	0.22	22.00	0.20	9.57	0.14	45,117
1990	52.23	0.18	1.67	0.05	4.77	0.08	58.67	0.18	34.26	0.17	7.07	0.09	76,453
1995	37.84	0.12	1.44	0.03	3.07	0.04	42.35	0.12	53.72	0.12	3.93	0.05	173,559
1997	42.42	0.14	1.32	0.03	2.59	0.05	46.34	0.15	49.04	0.15	4.62	0.06	116,187
2000	46.68	0.13	1.36	0.03	2.50	0.04	50.53	0.13	45.47	0.13	4.00	0.05	144,068
<b>13 years after award <sup>a</sup></b>													
1980	53.25	0.24	3.88	0.09	9.88	0.14	67.02	0.22	21.93	0.20	11.06	0.15	44,533
1985	52.42	0.24	3.12	0.08	7.99	0.13	63.53	0.23	25.39	0.20	11.08	0.15	45,117
1990	44.33	0.18	3.09	0.06	7.11	0.09	54.53	0.18	37.13	0.17	8.34	0.10	76,453
1995	32.98	0.11	2.38	0.04	4.10	0.05	39.46	0.12	55.85	0.12	4.69	0.05	173,559
1997	38.22	0.14	2.41	0.04	3.54	0.05	44.16	0.15	50.49	0.15	5.35	0.07	116,187

Continued

**Table 2.**  
**SSI and/or DI program participation and mortality experience of SSI children aged 0–17 at award, by award cohort and years after initial award:**  
**Percentage distribution of awardees by outcome—Continued**

Award cohort	SSI only		DI only		Concurrent (SSI/DI)		Any disability benefit (subtotal)		Neither SSI nor DI, alive		Dead		N
	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	
<b>15 years after award <sup>b</sup></b>													
1980	50.48	0.24	4.91	0.10	11.50	0.15	66.89	0.22	21.01	0.19	12.10	0.15	44,533
1985	46.56	0.23	4.33	0.10	9.69	0.14	60.58	0.23	27.29	0.21	12.14	0.15	45,117
1990	41.74	0.18	4.16	0.07	8.18	0.10	54.08	0.18	36.76	0.17	9.16	0.10	76,453
1995	31.50	0.11	3.34	0.04	4.77	0.05	39.61	0.12	55.20	0.12	5.19	0.05	173,559
<b>20 years after award <sup>c</sup></b>													
1980	40.23	0.23	8.20	0.13	15.02	0.17	63.46	0.23	21.69	0.20	14.85	0.17	44,533
1985	39.23	0.23	8.28	0.13	13.29	0.16	60.80	0.23	24.17	0.20	15.02	0.17	45,117
1990	37.96	0.18	7.74	0.10	10.54	0.11	56.24	0.18	32.33	0.17	11.44	0.12	76,453
<b>25 years after award <sup>d</sup></b>													
1980	32.06	0.22	12.37	0.16	15.68	0.17	60.11	0.23	21.92	0.20	17.98	0.18	44,533
1985	32.97	0.22	12.53	0.16	13.29	0.16	58.79	0.23	23.20	0.20	18.01	0.18	45,117
<b>30 years after award <sup>e</sup></b>													
1980	26.48	0.21	16.47	0.18	14.87	0.17	57.82	0.23	20.93	0.19	21.25	0.19	44,533

SOURCE: Authors' calculations using SSA administrative records.

NOTES: Rounded components of percentage distributions do not necessarily sum to 100.

DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

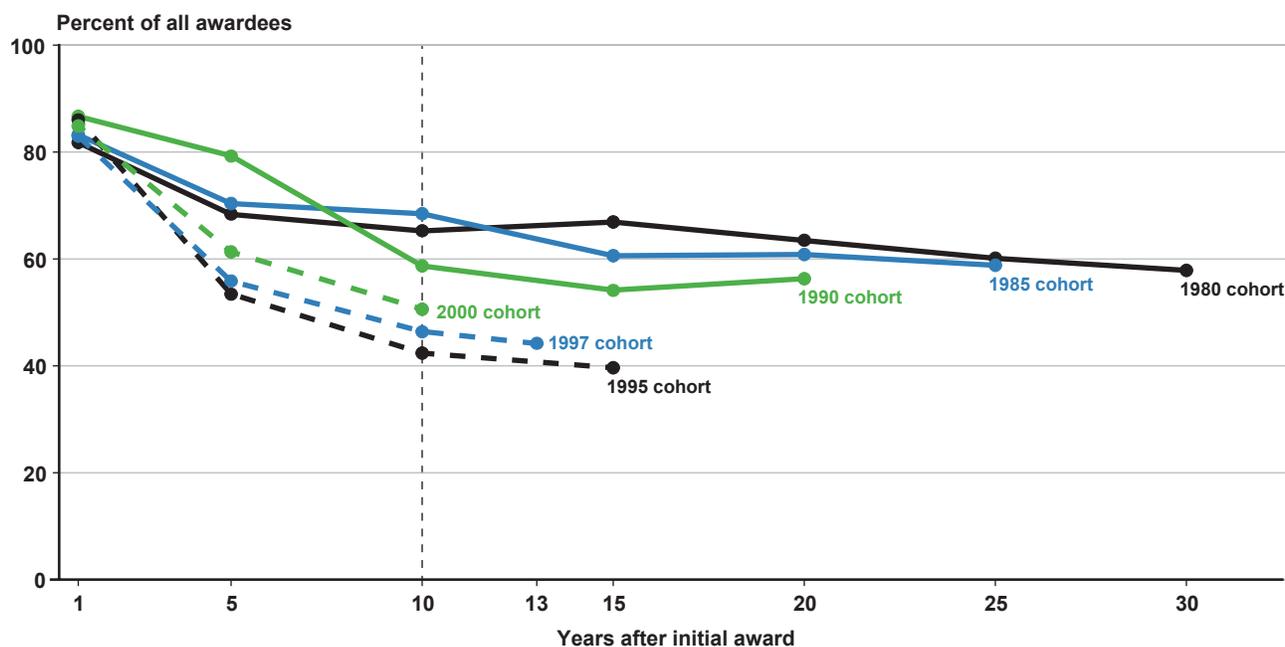
- a. Data for 2000 are not included because 13 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).
- b. Data for 1997 and 2000 are not included because 15 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).
- c. Data for 1995, 1997, and 2000 are not included because 20 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).
- d. Data for 1990, 1995, 1997, and 2000 are not included because 25 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).
- e. Data for 1985, 1990, 1995, 1997, and 2000 are not included because 30 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).

both of SSA's disability programs, especially as the cohorts age. Thirty years after initial award in 1980, more than half of surviving beneficiaries had some DI benefit receipt. Note, however, that although only less than half of disability awardees alive and receiving disability cash benefits in 2010 were in SSI-only status, about 7 in 10 of that group continued to receive SSI benefits. Second, accounting for death as an outcome is also increasingly important, as the awardee sample ages. More than 20 percent of all 1980 awardees died before 2010 (30 years after initial award), reflecting a level of mortality risk among those childhood awardees that seems very high compared with the mortality experience of the nondisabled population in the United States.<sup>11</sup> This represents more than half of initial awardees who had exited the rolls by 2010. The richness of the data in Table 2 reflects complex dynamics arising from a variety of sources. These data—reflecting variation in year of award, length of time since first award, and calendar year (not shown in the table explicitly)<sup>12</sup>—are important in understanding long-term changes, but the relationships are complex. In addressing the remaining research questions, we dissect this complexity by focusing on the various competing risks that affect the pattern of outcomes.

### Research Question 2: What Proportion of Awardees in the 1980–2000 Cohorts Receives Disability Benefits (SSI and/or DI) During Various Time Horizons?

Chart 3 shows the percentages of child awardees of all ages in disability benefit status at various time points (1 year to at least 10 years, and up to 30 years from initial SSI award in childhood).<sup>13</sup> Those rates include awardee participation in the SSI and/or DI programs (disabled-worker and/or auxiliary benefits). There is substantial variability here, but some differences are striking. First, the proportion of awardees receiving disability benefits generally declined in the years after first award for all cohorts. Second, for the earliest three cohorts (1980, 1985, 1990) well over half of awardees still received SSI and/or DI 10 years after the initial award, and 56–59 percent received some disability benefit 20–30 years after first award. Third, there is a clear drop—roughly 15 percentage points—between the 1990 and 1995 cohorts in the percentage of awardees receiving benefits 5–15 years from first award. Although there is a tendency for an increase between the 1995 and later cohorts in the percentage of awardees receiving benefits, the 1997 and 2000 cohorts still had much lower rates of benefit receipt

**Chart 3.** Percentage of childhood SSI awardees receiving SSI and/or DI benefits, by award cohort and years after initial award



SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

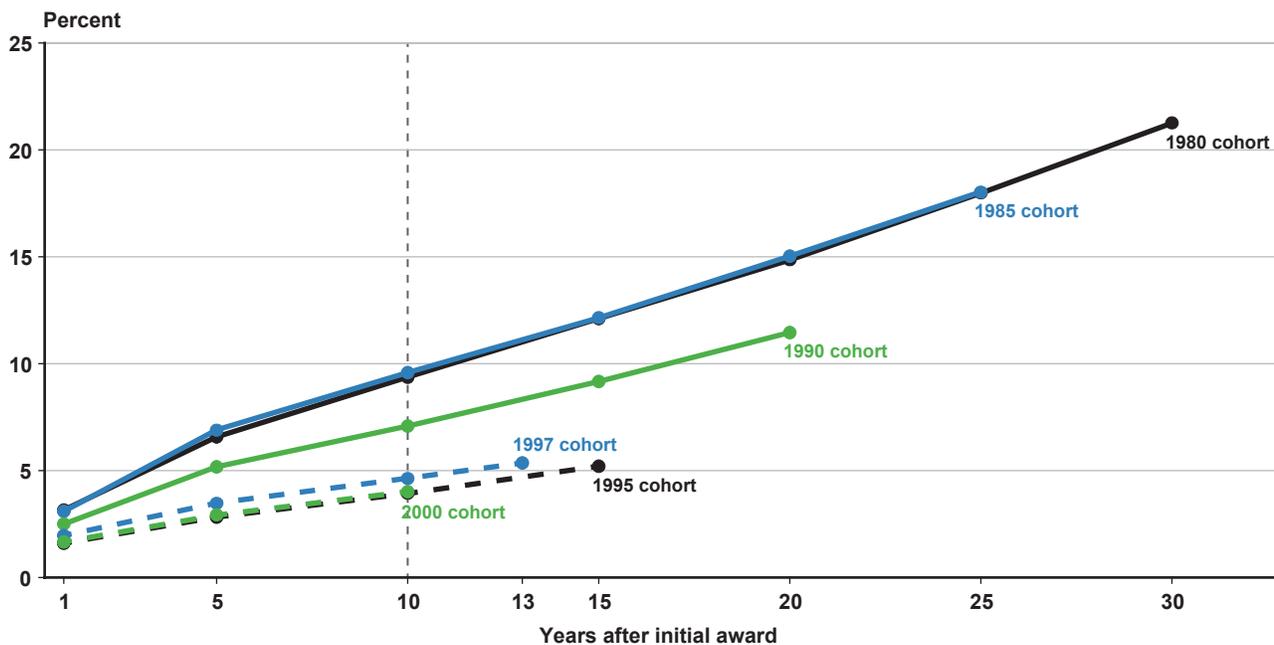
10 years after initial award, compared with the early cohorts (1980, 1985, 1990). The chart shows a dotted vertical line at 10 years from initial award to indicate the relative position of the various award cohorts. This keeps the time horizon comparable. There is a clear clustering of the observations, with earlier award cohorts (1980, 1985, and 1990) displaying a higher degree of benefit receipt at the 10-year mark roughly in the 60–70 percent range, while the 1995, 1997, and 2000 award cohorts display rates in the 40–50 percent range. In the next sections, we examine the role of various factors in affecting these trends.

**Research Question 3: What Are the Trends in Survival Trajectories Across the Six Award Cohorts?**

Because the risk of death and other factors suggesting the presence of severe and persistent medical conditions are important determinants of disability awards, it is not surprising that the mortality rate of child awardees was relatively high and increased as the cohorts aged. Chart 4 shows the mortality experience of the six award cohorts between 1980 and 2000 for up to 30 years after initial award. A useful way to compare those trajectories is based on cohort

differences in the proportion of awardees that had died at comparable points after the year of first award. Again, we included a dotted vertical line at year 10 to facilitate comparisons across award cohorts. The mortality trajectories show a widening gap as the cohorts age. Thus, the chart shows an unambiguous decline in mortality risk across the award cohorts, from the highs of the 1980 and 1985 award cohorts to substantial drops occurring between the 1985 and 1990 cohorts and between the 1990 and 1995 cohorts. The 1980 and 1985 cohorts’ mortality rates are roughly identical 10 years after award, followed by a clear decline for the 1990 cohort, and further drops for the 1995, 1997, and 2000 cohorts. As a result, the proportion of awardees that died within 10 years of award dropped from about 9–10 percent for the 1980 and 1985 cohorts, to roughly 4–5 percent for the 1995, 1997, and 2000 award cohorts, a decline of roughly 50 percent. Other things equal, a decline in mortality should be associated with an increase in benefit receipt; but in Charts 3 and 4, we observe the opposite pattern. A major conclusion from the charts is that the decline in mortality across award cohorts does not explain the decrease in the percentage of awardees receiving SSI and/or DI between the earlier and more

**Chart 4. Mortality experience of childhood SSI awardees, by award cohort and years after initial award**



SOURCE: Authors’ calculations using SSA administrative records.  
 NOTE: SSA = Social Security Administration; SSI = Supplemental Security Income.

recent cohorts. Later in our discussion, we explain this seeming contradiction.

This decline in mortality may be the result of changes in the observable characteristics of awardees (such as age, sex, and type of impairment) or of changes in the unobserved variables (such as the nature and severity of disabilities among awardees). We note that the data do not allow the use of a detailed diagnostic classification because of the lack of comparability over time that we encounter at a more disaggregated level, and therefore we observe only diagnostic shifts at a highly aggregated level; a lot of possibly relevant diagnostic detail remains unobserved. (However, as previously mentioned, our results are robust to other diagnostic groupings.) In addition, advances in medical treatments, which are also unobserved in our data set, may have contributed to the secular decline in mortality. We note that the results of our multiple regression analyses (Appendix Tables A-1 and A-2) suggest that changes in age, sex, and our diagnostic classification groupings do not explain the secular downward shift in mortality risk across award cohorts. For example, we observe that the proportion of awardees that died within 5 years of initial award dropped from 6.9 percent to 2.9 percent between the 1985 and 2000 award cohorts (next to last column of Tables A-1 and A-2); this is a huge drop in mortality risk. Holding the observed mix of awardees constant at the levels of the 2000 award cohort, but applying the 1985 model (discussed in detail later), we observe that the projected proportion of awardees that died 5 years after award for the 2000 award cohort was much higher (7.9 percent) than the proportion we actually observe for the 2000 award cohort (2.9 percent). This is not explained by changes in observed awardee characteristics because we held those constant; it is the result of unobserved factors affecting mortality risk between the 1985 and 2000 award cohorts. Indeed, the 7.9 percent death rate for the 2000 award cohort as predicted by the 1985 model is close to the 6.9 percent observed rate of death for the 1985 award cohort. Because the projection for the 2000 award cohort is slightly higher than the observed death rate for the 1985 award cohort, factors other than the observed awardee mix explain the entire observed decline in the probability of death 5 years after award between the 1985 and 2000 award cohorts. Other comparisons (not detailed here) between observed and predicted death rates at various time points after award show a similar pattern. Hence, we conclude that observed changes

in awardee mix by type of impairment do not explain the overall pattern of declining mortality rates at comparable time points after initial award across the six cohorts.

The observed decline in mortality may have been affected by the 1990 modification of the Listing of Impairments and the Supreme Court's *Zebley* decision (also in 1990)—both liberalizing the disability screen and presumably resulting in awards to children with less severe physical and mental impairments. However, the tightening of eligibility under welfare reform, and notably the age-18 re-determination, could have had effects in the opposite direction. Yet, we do not observe clear discontinuities in trajectories, and the secular decline continues for the post-PRWORA cohorts. Therefore, we suggest caution in interpreting the changes and point out that broader secular trends in society are possibly quite important here. Specifically, improvements in the efficacy of medical care may have produced a profound gradual decline in mortality across award cohorts and time. We speculate that innovations may have reduced mortality from causes such as low birth weight, childhood cancers, and severe physical diagnoses such as autoimmune disorders or cystic fibrosis. However, our study was not designed to separate the effect of improvements in medical technology from the many programmatic changes influencing case severity.

Other things equal, a reduction in mortality risk should increase the risk of program participation. However, trends in the proportion of survivors transitioning to nonparticipation status also play a role. The next research question addresses this issue.

#### ***Research Question 4: What Are the Trends in the Trajectory of Disability Program Participation and Nonparticipation Among Survivors?***

In addition to mortality, the other major determinant of duration on the disability rolls and lifetime program cost is the pattern of participation and nonparticipation among survivors. As previously noted, we do not make a value judgment on the desirability of shifting from participant to nonparticipant status for individual disability beneficiaries; under any circumstances, that would be a daunting task, given the enormous heterogeneity in the nature and severity of disabilities among surviving program participants, their work potential, and labor market opportunities after a period of no or

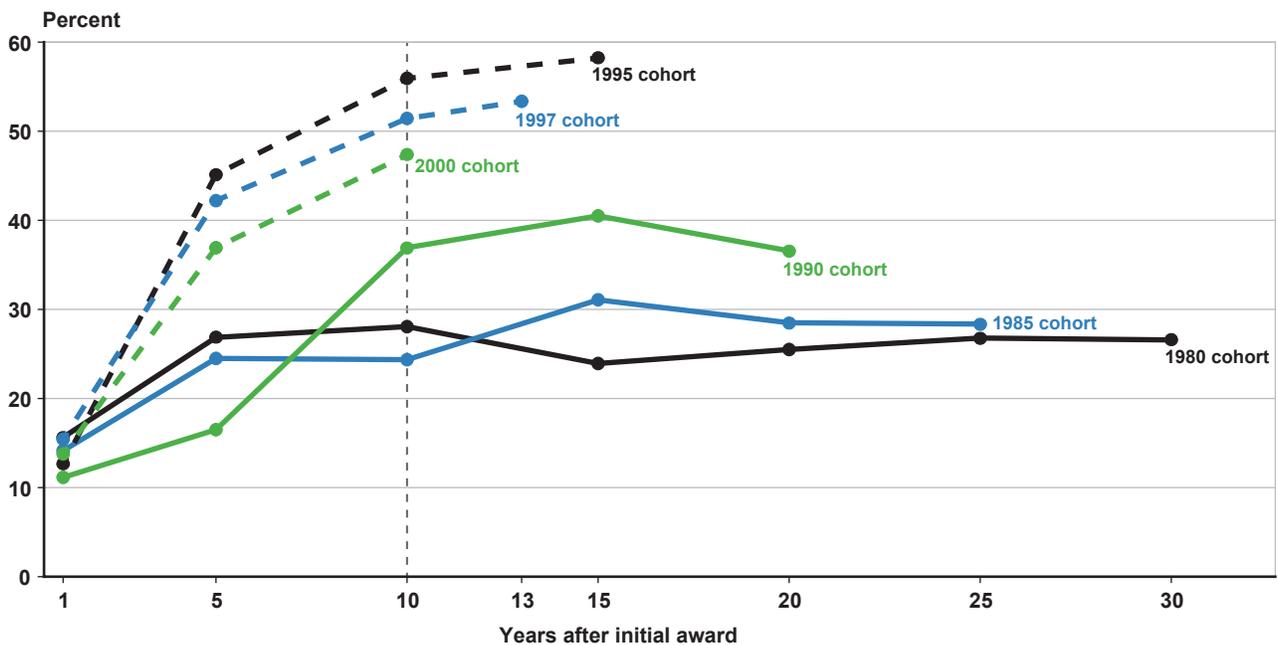
limited employment. Here, we simply assess whether there are observable trends in the trajectory of disability program participation and nonparticipation among childhood SSI awardees and whether any shifts in awardee characteristics explain those trends.

Chart 5 gives the percentages of *survivors* who were off the disability rolls (both SSI and DI), using a time horizon of up to 30 years across the six award cohorts. This chart maps the percentage of awardees in each cohort receiving neither SSI nor DI benefits over time (conditional on being alive), using the year of award as the anchoring point of comparable time intervals. The chart shows a clear break between the trajectories of the three award cohorts that entered the program rolls between 1980 and 1990 and the three award cohorts entering between 1995 and 2000. Overall, the percentage of survivors receiving neither SSI nor DI 1 year after award has remained relatively level, between 11 percent and 16 percent for each cohort. Chart 5 explains the seeming puzzle noted in the discussion of Charts 3 and 4, where the decline in mortality across award cohorts does not explain the decrease in the percentage receiving SSI and/or DI benefits between the earlier and more recent cohorts. Clearly, the strong increase in the percentage

of surviving awardees not receiving benefits explains the decrease in participation between earlier and later award cohorts presented in Chart 3—*despite* the corresponding, but smaller, downward shift of mortality trajectories reflected in Chart 4, which affects the overall rate of participation among awardees in the opposite direction.

A more refined picture emerges when we analyze disability program nonparticipation by calendar year in the analysis. Chart 6 shows the same information that was included in Chart 5, but uses calendar year on the horizontal axis. For example, when looking at the first panel, we see that 1 year after award for the 1980 cohort is 1981, while the corresponding point is 1986 for the 1985 award cohort. Likewise, in 2010, we observe the 1980 award cohort 30 years after first award, but the corresponding calendar-year point is only 25 years after first award for the 1985 award cohort. The four panels contain the same information, but highlight different award cohorts. Panel 1 shows that after an initial increase in the proportion of awardees not receiving benefits up to 5 years after award, both the 1980 and 1985 cohort trajectories are basically flat and remain under 30 percent for all but one data point.

**Chart 5.**  
**Percentage of surviving childhood SSI awardees receiving neither SSI nor DI disability benefits, by award cohort and years after initial award**



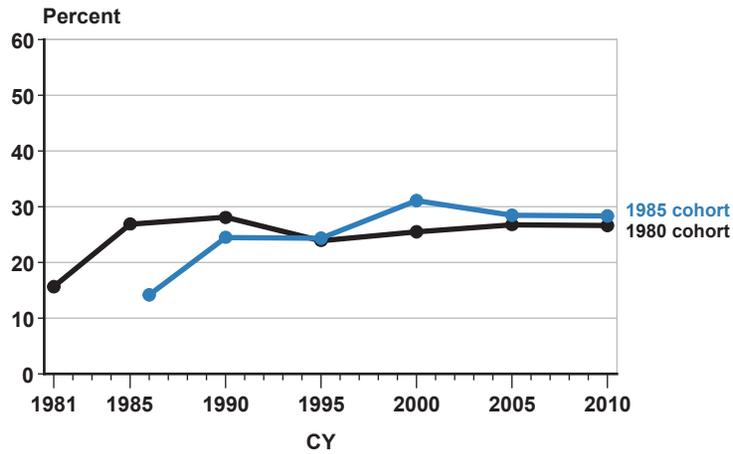
SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

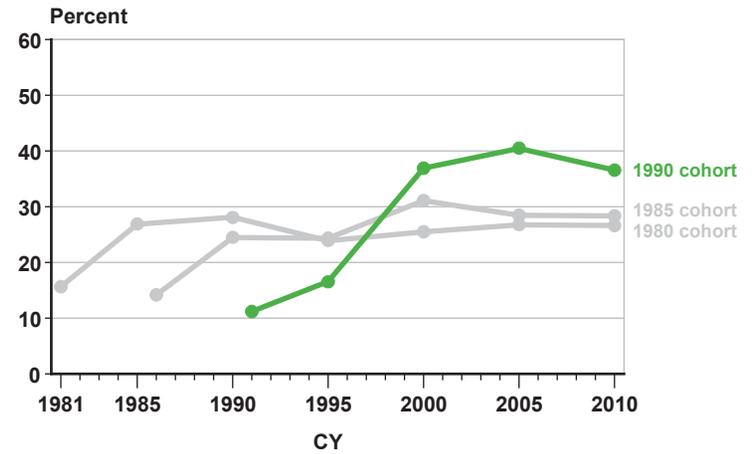
**Chart 6.**

**Percentage of surviving childhood SSI awardees receiving neither SSI nor DI disability benefits, by award cohort and calendar year (CY)**

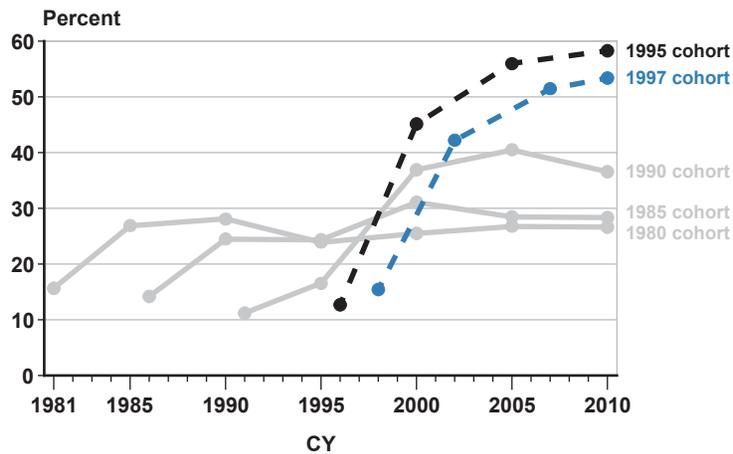
*Panel 1: 1980 and 1985 cohorts*



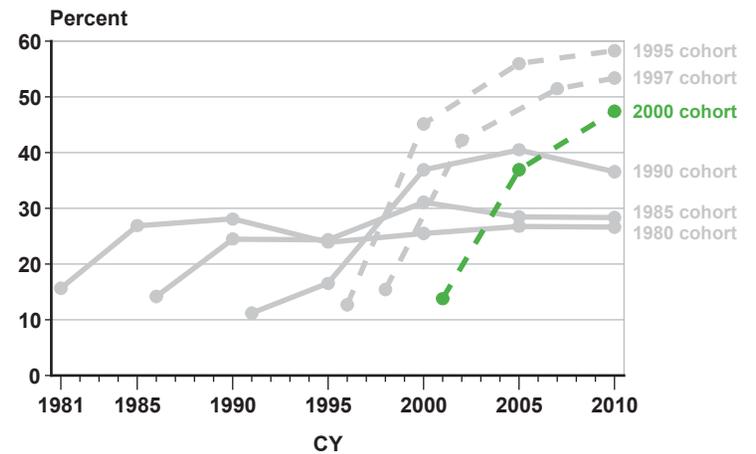
*Panel 2: 1990 cohort*



*Panel 3: 1995 and 1997 cohorts*



*Panel 4: 2000 cohort*



SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

In contrast, panel 2 shows that for the 1990 award cohort, there is a sharp uptick in the trajectory between 5 and 10 years after award—corresponding to the 1995 to 2000 interval. Although because of our sample construction, we do not observe the proportions in 1996 directly, it is clear that individuals who were still in benefit status 6 years after award were exposed to the changed policy regime of the 1996 welfare reform. While some individuals in the 1980 and 1985 award cohorts also survived in benefit status until after 1996, most of those earlier entrants were already in benefit status for 11 to 16 years after award. This is long enough to anticipate essentially no responsiveness to the new policy regime introduced in 1996. Moreover, many members of these earlier cohorts were well into adulthood by 1996, and thus not subject to the mandatory age-18 redetermination required by welfare reform. For the 1990 award cohort, the trajectory reaches a clearly higher level, up to 40 percent, compared with the earlier award cohorts, which hover around 30 percent.

Panel 3 shows the two award cohorts bracketing the year of the welfare reform—1996. Clearly, the vast majority of 1995 awardees were subject to the changed policy regime introduced by the 1996 welfare reform, while all of the 1997 awardees were subject to the policy environment after welfare reform. We see a much stronger upward shift (approaching the 55–60 percent range) in the trajectories of later award cohorts not receiving disability benefits, compared with the trajectories of the 1990 and earlier award cohorts. Finally, panel 4 shows that there is some downward shift in the trajectory for the 2000 award cohort, but that trajectory approaches 50 percent, even for this most truncated follow-up period. We see a modest downward shift from the 1995 to 1997 to 2000 award cohorts, but it is clear that the slope of those three trajectories remains steeper than the trajectories of the earlier three award cohorts.

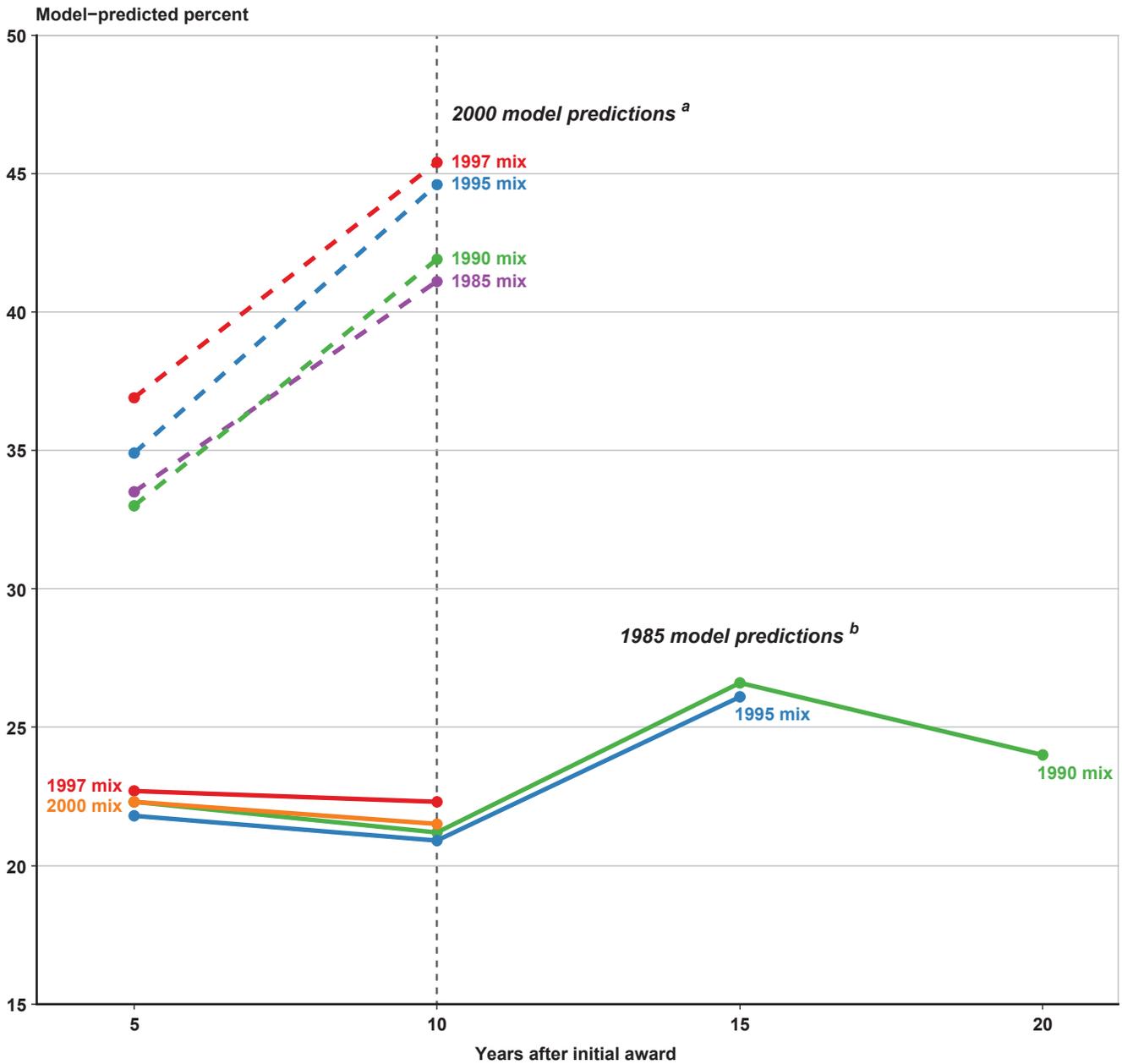
For the most part, both the time elapsing since first award and the calendar year of the observed participation outcome appear to affect program participation. We observe a sharp upward shift in the slope of trajectories toward increased proportions of survivors off the rolls around the time of the 1996 welfare reform—a trend that appears to be diminishing for the recent cohorts. These observed patterns may be related to changes in SSI policies and implementation practices affecting the trends in the characteristics of awardees and exits. This is unsurprising given the increased likelihood of a cessation that is due to a

CDR or an age-18 redetermination following welfare reform. Although the earlier liberalization of SSI policy in 1990 (particularly *Zebley*) may have also played a role in disability program nonparticipation, we simply do not have the evidence to support that plausible claim. We also note that the observed patterns may also be influenced by other factors such as the business cycle, trends in the use and effectiveness of medical and rehabilitation technologies, and civil rights protections pursuant to the Americans with Disabilities Act of 1990. We cannot directly test those factors and other explanations with our data, but we can explore whether changes in the characteristics of awardees by age, sex, and broad type of impairment explain all or part of the shift in patterns of disability nonparticipation. For these compositional factors to provide any explanation of changes across award cohorts, at a minimum we need to be able to observe changes in awardee characteristics over time and differences in outcomes among subgroups identified by these variables.

As shown in Table 1, we do indeed observe substantial changes in awardee mix in terms of age, sex, and broad impairment type, and therefore we now turn our attention to the question of whether those differences explain the shifts in patterns of disability nonparticipation shown in Chart 5. To identify the influence of those factors, we first run multinomial logit regressions on our five potential outcome statuses—controlling for age (in single-year dummy variables), sex, and type of impairment (see Table 1 for groupings) for 1985 (first year with reliable diagnostic data) and 2000. The results from those regressions are included in supplementary tabulations available for interested readers.<sup>14</sup> Next, using the observed mix of awardees for each cohort and follow-up observation point, we calculate the projected percentage of all awardees alive and in non-program status using (a) the 1985 model and (b) the 2000 model. Subsequently, we scale up the projected fractions as a percentage of those awardees who were alive, to make the results of the projections directly comparable to Chart 5 data, which are conditioned on survivor status.<sup>15</sup>

The results given in Chart 7 show that the projected percentage of awardees off the rolls is not sensitive to observed awardee mix for the given cohort. The chart presents two sets of predictions, generated respectively by the 2000 model and the 1985 model. As it happens, the 2000 model predictions are at the top of the chart, while the 1985 model predictions are at the

**Chart 7.**  
**Model-predicted percentage of surviving childhood SSI awardees receiving neither SSI nor DI disability benefits, by award cohort and years after initial award**



SOURCE: Authors' calculations using SSA administrative records.

NOTES: SSA = Social Security Administration; SSI = Supplemental Security Income.

- a. Predictions are based on the estimated coefficients of the 2000 model applied to the characteristics of the 1985, 1990, 1995, and 1997 awardees.
- b. Predictions are based on the estimated coefficients of the 1985 model applied to the characteristics of the 1990, 1995, 1997, and 2000 awardees.

bottom. This is not based on an arbitrary decision, but reflects the results of this sensitivity analysis. The top four lines show the predicted outcomes of the 1985, 1990, 1995, and 1997 childhood award cohorts using the 2000 cohort multinomial logit regression weights (that is, the coefficients from the 2000 regression). While there may be a slight upward shift across award cohorts, the overall slope of the lines is fairly parallel, as there is a similar increase in nonreceipt of disability benefits for each cohort. The bottom four lines show the predicted outcomes of the 1990, 1995, 1997, and 2000 childhood award cohorts using the 1985 multinomial logit regression weights (that is, the coefficients from the 1985 regression). While there is some variation, the projections are relatively flat and are clearly bundled. The 2000 model clearly projects a degree of nonparticipation in the SSI and/or DI program well above 30 percent—regardless of the mix of the award cohort on the characteristics measured (age, sex, and overall type of impairment). By contrast, the 1985 model consistently generates predictions well below 30 percent.

We conclude, therefore, that awardee mix on the variables our models account for does not play a substantial role in explaining the observed trajectories in Chart 5. Thus, the observed pattern of discontinuity in trajectories across award cohorts is not explained by differences in age, sex, or type of impairment across the cohorts. Rather, it reflects the nature of the SSI program as it existed in the year of the model (1985 or 2000). Simply stated, the disability programs as they existed in 1985 were conducive to a much higher level of continued participation than the program conditions that prevailed in 2000. Although we still cannot positively identify other reasons that explain the detailed patterns, it is notable that the discontinuity that is displayed in Charts 5 and 6, which roughly coincides with the welfare reform of 1996, is not the result of changes in the observed mix of awardees. We also know that welfare reform included two important provisions designed to increase exits: the newly mandated age-18 redetermination and the 3-year CDR schedule mandated for children who were expected to medically improve. Both of those factors should increase nonparticipation irrespective of changes in awardee mix. In addition, the interpretation that changes in the trajectory of nonparticipation are related to the welfare reform is strengthened by the fact that shifts in nonparticipation trajectories are observed for both new awardees and those already

on the rolls at the time of the welfare reform. In sum, our findings are consistent with prior expectations about the effects of the welfare reform.<sup>16</sup> Although we urge caution in interpreting our findings, it should be noted that we are unaware of any other coherent hypotheses that would provide an explanation for our findings.

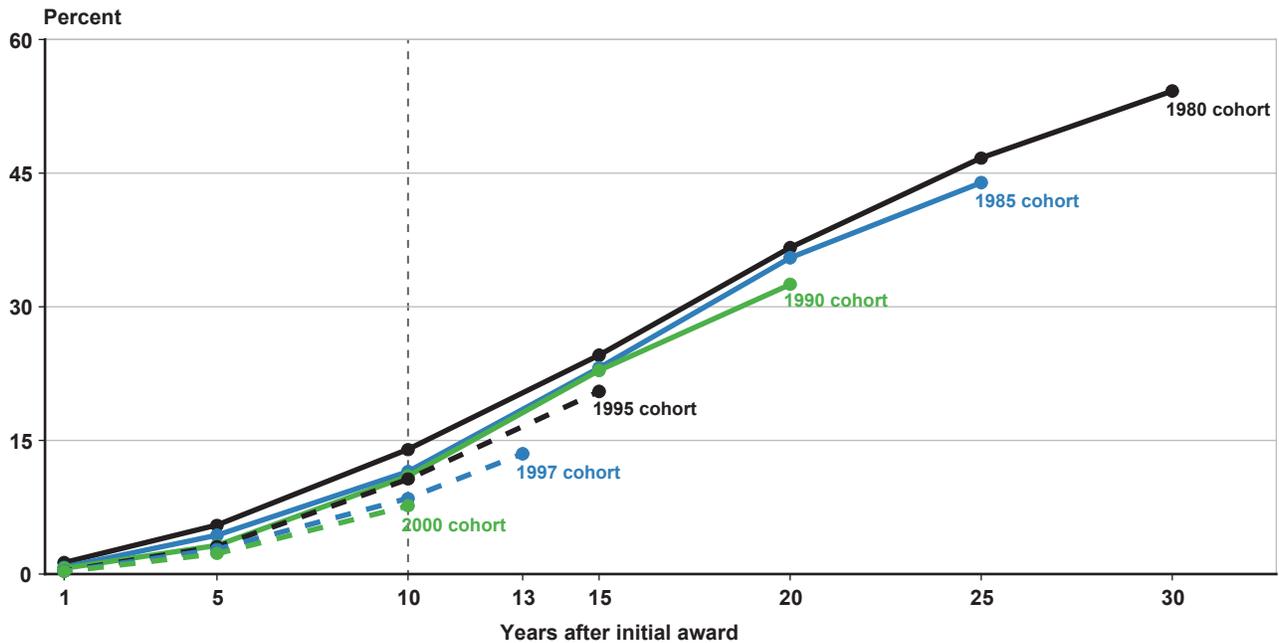
#### ***Research Question 5: What Are the Trends in Shifting to DI or Concurrent Status Among Surviving Disability Beneficiaries and What Is the Contribution of Disabled-Worker and Auxiliary Benefit Receipt in Adulthood?***

Transitions to DI benefit status (either as DI-only or concurrent SSI and DI) among surviving disability beneficiaries in adulthood is important because the DI program is generally more generous than SSI because it is not means tested and because of interactions involving Medicaid and Medicare coverage. Burkhauser and Daly (2011) highlighted the potential importance of that transition for beneficiary well-being, but provided no empirical estimates of the magnitude of the receipt of disabled-worker benefits among childhood awardees over the adult life cycle. We fill that gap and also address an additional issue—the possibility of an SSI recipient receiving DI benefits not because of earning DI-insured status and, as a result, disabled-worker benefits, but because of his or her eligibility for auxiliary benefits as a surviving dependent of a Social Security beneficiary.<sup>17</sup>

Chart 8 presents the percentage of surviving childhood SSI awardees receiving DI benefits up to 30 years after their first SSI award. The results show the increasing importance of DI receipt over time for all of the award cohorts as childhood awardees age into adulthood. Well over half of the 1980 award cohort that was still receiving some form of disability benefits 30 years after initial award received DI benefits, including some who received both SSI and DI. The trajectories are roughly parallel across award cohorts, especially for the 1980, 1985, and 1990 award cohorts, suggesting that the experience of the 1980 cohort may be a good approximation for projecting the experience of at least some of the more recent cohorts into the future. However, there is a slight downward trend in the proportion of awardees receiving DI benefits across cohorts. That downward shift across cohorts is fairly apparent 10 years after award, with a high of 14 percent for the 1980 cohort and a low of 8 percent for the 2000 cohort.

**Chart 8.**

**Percentage of surviving childhood SSI awardees receiving DI benefits (DI only or concurrent DI/SSI), by award cohort and years after initial award**



SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

The cohort differences are more muted as we move toward the out-years.

However, the intercohort differences may not be simply generalized to disabled-worker benefits because changes in the mix of disabled-worker and auxiliary benefit receipt greatly complicate the picture. Table 3 highlights the key comparisons. It provides the percentages of childhood SSI awardees receiving disabled-worker and auxiliary benefits among DI-only beneficiaries and awardees receiving concurrent benefits. Estimates for the two types of benefits (disabled-worker and auxiliary) under both categories tend to add to well over 100 percent because some individuals receive both types of benefits. First, we note that auxiliary beneficiaries are a substantial portion of both DI-only and concurrent benefit recipients across all cohorts, especially at the beginning of the adult life cycle (age 20); as people age, however, the proportion of disabled workers substantially increases. Second, keeping age constant, there is a clear trend of increases in the shares of awardees receiving disabled-worker benefits, especially among DI-only beneficiaries.

Table 4, which shows disabled-worker and auxiliary beneficiaries as a percentage of all surviving awardees, refines the picture. The percentage of childhood SSI awardees receiving either or both disabled-worker and auxiliary benefits clearly increases as those youths age. However, holding age constant, there is no discernible trend in the percentage of survivors receiving disabled-worker benefits across award cohorts. Yet, devising strategies to increase this type of transition in the future, as advocated by Burkhauser and Daly (2011), may be a promising direction for future experimentation and policy development.<sup>18</sup>

Finally, we note that there appears to be a decline in the proportion of individuals receiving auxiliary benefits across award cohorts, at any given age. We do not fully understand the reasons for that decline. Part of the decline may result from a reduction of the severity of childhood disabilities in the *Zebley* era (particularly for the 1995 cohort) and a relative increase after the PRWORA. However, whatever the causes may be, the secular decline in the proportion of auxiliary benefit receipt among childhood SSI awardees may be the reason behind the slight downward shift in trajectories across the award cohorts observed in Chart 8.

**Table 3.****Percentage of childhood SSI awardees receiving DI disabled-worker or auxiliary benefits among DI-only and concurrent (SSI/DI) beneficiaries, by award cohort and age**

Award cohort	DI-only beneficiaries receiving given benefit <sup>a</sup>					Concurrent (SSI/DI) beneficiaries receiving given benefit <sup>b</sup>				
	Disabled-worker		Auxiliary		N	Disabled-worker		Auxiliary		N
	Estimate	Standard error	Estimate	Standard error		Estimate	Standard error	Estimate	Standard error	
<b>Age 20</b>										
1980	16.1	1.0	92.0	0.8	1,244	21.9	0.7	84.6	0.6	3,703
1985	21.3	1.2	86.9	1.0	1,231	25.3	0.7	80.5	0.6	3,805
1990	24.3	1.0	85.6	0.8	1,788	26.7	0.6	80.0	0.5	5,464
1995	34.1	1.2	77.3	1.1	1,576	33.1	0.6	72.9	0.6	5,368
1997	32.9	1.6	79.6	1.4	817	34.7	0.9	72.4	0.9	2,684
2000	35.7	1.8	76.0	1.6	672	29.5	0.9	76.6	0.9	2,414
<b>Age 25</b>										
1980	40.6	1.0	66.8	1.0	2,443	46.5	0.6	59.1	0.6	6,335
1985	48.2	1.0	58.6	0.9	2,758	52.0	0.6	53.1	0.6	6,092
1990	57.9	1.0	49.0	1.0	2,674	55.2	0.6	48.7	0.6	6,232
1995	69.2	0.9	37.9	0.9	2,721	61.3	0.7	42.8	0.7	5,380
1997	67.9	1.3	40.2	1.4	1,294	60.1	1.0	43.7	1.0	2,323
2000	66.2	1.7	42.5	1.8	749	52.9	1.3	51.5	1.3	1,398
<b>Age 30 <sup>c</sup></b>										
1980	50.1	0.8	57.1	0.8	3,980	46.3	0.6	59.7	0.6	6,972
1985	56.1	0.9	50.0	1.0	2,768	52.7	0.8	52.6	0.8	4,424
1990	65.9	0.9	39.6	1.0	2,530	55.3	0.8	48.5	0.8	3,786
1995	73.8	1.1	31.8	1.1	1,697	61.0	1.1	42.8	1.1	2,101
<b>Age 35 <sup>d</sup></b>										
1980	51.2	0.8	55.3	0.8	4,077	45.3	0.7	61.1	0.7	5,502
1985	56.8	1.0	49.7	1.1	2,231	50.2	0.9	55.5	0.9	2,827
1990	63.0	1.4	42.5	1.4	1,247	48.3	1.3	56.5	1.3	1,543

SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

- The denominator for the percentage calculations in each row is childhood SSI awardees in the award cohort who had transitioned to DI-only status at the given age.
- The denominator for the percentage calculations in each row is childhood SSI awardees in the award cohort who had transitioned to concurrent SSI/DI status at the given age.
- Data for 1997 and 2000 are not included because childhood SSI awardees in those years could not have reached age 30 by the end of our observation period (2010).
- Data for 1995, 1997, and 2000 are not included because childhood SSI awardees in those years could not have reached age 35 by the end of our observation period (2010).

**Table 4.**  
**Percentage of all surviving childhood SSI awardees receiving DI disabled-worker, auxiliary, or both types of benefits, by award cohort and age**

Award cohort	All surviving SSI childhood awardees receiving given benefit <sup>a</sup>						N
	Disabled-worker		Auxiliary		Either or both types		
	Estimate	Standard error	Estimate	Standard error	Estimate	Standard error	
<b>Age 20</b>							
1980	2.5	0.1	10.7	0.2	12.4	0.2	39,975
1985	3.0	0.1	10.3	0.2	12.5	0.2	40,215
1990	2.7	0.1	8.4	0.1	10.3	0.1	70,275
1995	2.1	0.0	4.7	0.1	6.4	0.1	108,480
1997	2.4	0.1	5.1	0.1	6.9	0.1	50,724
2000	2.1	0.1	5.2	0.1	6.7	0.1	45,732
<b>Age 25</b>							
1980	10.2	0.2	13.9	0.2	22.6	0.2	38,783
1985	11.6	0.2	12.5	0.2	22.8	0.2	38,876
1990	10.8	0.1	9.4	0.1	19.2	0.2	46,378
1995	8.7	0.1	5.6	0.1	13.6	0.1	59,746
1997	9.8	0.2	6.6	0.2	15.6	0.2	23,184
2000	9.3	0.3	7.8	0.2	16.1	0.3	13,302
<b>Age 30 <sup>b</sup></b>							
1980	13.9	0.2	17.1	0.2	29.2	0.2	37,534
1985	15.3	0.2	14.6	0.2	28.3	0.3	25,390
1990	14.0	0.2	10.5	0.2	23.5	0.3	26,905
1995	12.6	0.2	7.2	0.2	18.9	0.3	20,103
<b>Age 35 <sup>c</sup></b>							
1980	16.8	0.2	20.6	0.2	35.2	0.3	27,227
1985	17.8	0.3	17.7	0.3	33.5	0.4	15,092
1990	15.7	0.4	14.4	0.4	28.7	0.5	9,721

SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

- a. The denominator for the percentage calculations in each row is all surviving childhood SSI awardees in the award cohort at the given age, including SSI-only beneficiaries, concurrent SSI/DI beneficiaries, DI-only beneficiaries, and those off the rolls and alive.
- b. Data for 1997 and 2000 are not included because childhood SSI awardees in those years could not have reached age 30 by the end of our observation period (2010).
- c. Data for 1995, 1997, and 2000 are not included because childhood SSI awardees in those years could not have reached age 35 by the end of our observation period (2010).

## Discussion

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Based on early studies on the then nascent SSI program, we know that historically—compared with other means-tested programs—the average duration on the SSI rolls is fairly long, especially among childhood awardees (Rupp and Scott 1995). Still, as the more recent study by Davies, Rupp, and Wittenburg (2009) has demonstrated, SSI benefit receipt among childhood awardees substantially drops over time, and that decline continues well into adulthood. Those authors also found some evidence that the participation patterns may change from early cohorts of awardees (1980) to more recent cohorts (1997). In this article, we expand that research in two different directions. First, we look at a much more complex array of outcomes, including DI participation in adulthood, and we distinguish between death and program nonparticipation among survivors. Second, we also compare outcome trajectories for six different cohorts of awardees spanning from 1980 to 2000 and follow them for up to 30 years after first award.

We find that a nontrivial portion of childhood SSI awardees died over longer time horizons, and that mortality has generally decreased for successive cohorts. Mortality, of course, also reduces the duration of SSI participation. A relatively more important factor that also reduces SSI duration is transition to nonbeneficiary status among survivors. By contrast, access to DI benefits increases the overall duration of disability cash benefit receipt. Indeed, 30 years after their initial SSI award, a higher portion of 1980 awardees received DI benefits (both disabled-worker and auxiliary, some concurrently with SSI benefits) than SSI-only benefits.

We also address how these trajectories have changed across award cohorts. Although it is common knowledge that SSI program rules affecting childhood awardees have changed substantially since the start of the SSI program in 1974, there is scant evidence of the changes in the *trajectories* of program participation. In comparing the trajectories of the various award cohorts, we find evidence that these changes have been substantial. In particular, we find that the proportion of childhood awardees that was still receiving any disability benefits (SSI and/or DI) at various years since first award had generally dropped across award cohorts over time, with a particularly strong break between the 1990 and 1995 award cohorts.

We also find suggestive evidence that welfare reform had a lasting effect on benefit receipt. Changes in the trajectories of program participation provide the empirical evidence. First, there is an upward shift in the nonparticipation trajectory for the 1990 cohort around the time of the welfare reform in the mid-1990s. Second, the slope of that trajectory shows a further dramatic upward shift between the 1990 and 1995 award cohorts. There is some reversion for the two most recent cohorts (1997 and 2000), but for the most part, the levels of nonparticipation are still much higher at comparable points for those cohorts than the levels observed for the earliest cohorts. Using multinomial logit regression, we show that awardee mix on observed variables (age, sex, type of impairment) does not explain this major secular change. We do find compelling evidence that is consistent with the hypothesis that the increase in exits stemming from welfare reform is an important source of reduced levels of overall disability program participation across award cohorts. Although transitions involving DI (disabled-worker or auxiliary) benefits are increasingly important over the individual life cycle as survivors age, the evidence suggests that there have been no major differences in disabled-worker benefit receipt across the award cohorts.

In a broader sense, our results are consistent with the notion that the SSI program has gone through substantial changes over time. The SSI program for children as it operates now is more dynamic than the early program was. Well into adulthood, the importance of death as a reason for exits has diminished, and exits to nonparticipation status among adult survivors have become much more common. This raises new policy questions about the financial well-being and labor market participation among childhood awardees in adulthood. One avenue for future research would be to explore more fully the contributors to changes in mortality over time—including medical advances and SSA policy changes—such as changes in the regulation basis identifying the reasons children are awarded SSI benefits.

Thus, our results reinforce the findings of previous analyses of the SSI program as it applies to children. Those analyses were informed by cross-sectional and time-series evidence, but not the kind of longitudinal analysis we present in this article. Some of the transformation in the SSI program has been related to policy changes, such as the Supreme Court's *Zebley*

decision and the 1996 welfare reform. Our results are consistent with the notion that those policy changes may have substantially altered the characteristics of awardees in a more subtle way than can be gleaned from observed changes in diagnostic and demographic characteristics and may have directly affected exits from the program. Of course, broader policy innovations—such as the Americans with Disabilities Act of 1990, improvement in the efficacy in medical treatments and assistive technologies, major changes in the diagnosis and treatment of mental disorders, and changes in the labor market—may have also influenced the observed trajectories.

Our results are consistent with previous research on adult awardees—suggesting the importance of SSI/DI program interactions—and the pattern of transitions from SSI to DI or concurrent status over the adult life cycle (Rupp and Riley 2011). Thus, the prospect of transitions to the DI program in adulthood should inform policies focusing on SSI children and young adults as well. SSA has been actively testing policy interventions to support the transition to adulthood for youth disability beneficiaries (see, for example, Fraker and Rangarajan (2009) for a discussion of the Youth Transition Demonstration Project, and Hemmeter (2014) for more information on short-term DI outcomes for that project). However, the transition to the DI rolls has been only a minor part of these interventions. There is clearly room to consider transition to DI-insured status among childhood SSI awardees as a

potentially important outcome that may be affected by active policy interventions in the future (Burkhauser and Daly 2011).

The increasing empirical importance of transitions to nonparticipant status in adulthood also suggests that the efficacy of employment-support policies and programs targeting transition-age youth is increasingly important as a policy issue. Transitions to both the DI program and nonbeneficiary status, however, raise broader issues about the effects those transitions have on one's overall well-being, which require the use of additional data—particularly data on earnings trajectories and on public health insurance coverage and utilization in adulthood (Rupp and Riley 2012). To fully assess disability program participation and the transition to adulthood, a crucial issue is their effect on one's financial well-being. An example of another perspective on long-term outcomes of SSI children is provided by Weathers and others (2008), who examined the role of postsecondary education for a group of deaf and hard-of-hearing SSI youths. Combining information on SSI and DI benefit amounts with earnings, health insurance coverage, and health services utilization data into adulthood would go a long way toward making comparisons—a much needed shift from a narrower focus on benefit expenditures from the government's perspective toward a broader array of outcomes affecting youth as they transition to adulthood.

## Appendix

**Table A-1.**

**SSI and/or DI program participation and mortality experience of childhood SSI awardees aged 0–17 at award, by award cohort and years after award: Actual and 1985 model-predicted percentage distribution of awardees by outcome**

Award cohort, model	SSI only		DI only		Concurrent (SSI/DI)		Neither SSI nor DI, alive		Dead	
	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error
<b>5 years after award</b>										
1985 characteristics, actual	67.3	0.2	0.7	0.0	2.4	0.1	22.8	0.2	6.9	0.1
1990 characteristics, actual	76.7	0.2	0.5	0.0	2.1	0.1	15.6	0.1	5.2	0.1
1990 characteristics, 1985 model	68.9	0.2	0.6	0.0	2.1	0.1	22.3	0.2	6.0	0.1
1995 characteristics, actual	51.8	0.1	0.4	0.0	1.2	0.0	43.8	0.1	2.8	0.0
1995 characteristics, 1985 model	69.0	0.3	0.5	0.0	1.9	0.1	21.8	0.2	6.8	0.2
1997 characteristics, actual	54.3	0.1	0.4	0.0	1.1	0.0	40.7	0.1	3.5	0.1
1997 characteristics, 1985 model	66.7	0.3	0.5	0.0	1.6	0.0	22.7	0.3	8.5	0.2
2000 characteristics, actual	59.9	0.1	0.3	0.0	1.1	0.0	35.8	0.1	2.9	0.0
2000 characteristics, 1985 model	67.7	0.3	0.4	0.0	1.6	0.0	22.3	0.2	7.9	0.2
<b>10 years after award</b>										
1985 characteristics, actual	60.6	0.2	2.0	0.1	5.9	0.1	22.0	0.2	9.6	0.1
1990 characteristics, actual	52.2	0.2	1.7	0.0	4.8	0.1	34.3	0.2	7.1	0.1
1990 characteristics, 1985 model	62.3	0.2	2.0	0.1	6.0	0.1	21.2	0.2	8.5	0.1
1995 characteristics, actual	37.8	0.1	1.4	0.0	3.1	0.0	53.7	0.1	3.9	0.0
1995 characteristics, 1985 model	62.4	0.3	1.8	0.1	5.7	0.1	20.9	0.2	9.2	0.2
1997 characteristics, actual	42.4	0.1	1.3	0.0	2.6	0.0	49.0	0.1	4.6	0.1
1997 characteristics, 1985 model	60.3	0.3	1.5	0.1	4.7	0.1	22.3	0.3	11.2	0.2
2000 characteristics, actual	46.7	0.1	1.4	0.0	2.5	0.0	45.5	0.1	4.0	0.1
2000 characteristics, 1985 model	61.3	0.3	1.6	0.1	5.2	0.1	21.5	0.2	10.4	0.2

Continued

**Table A-1.**

**SSI and/or DI program participation and mortality experience of childhood SSI awardees aged 0–17 at award, by award cohort and years after award: Actual and 1985 model-predicted percentage distribution of awardees by outcome—*Continued***

Award cohort, model	SSI only		DI only		Concurrent (SSI/DI)		Neither SSI nor DI, alive		Dead	
	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error
<b>15 years after award <sup>a</sup></b>										
1985 characteristics, actual	46.6	0.2	4.3	0.1	9.7	0.1	27.3	0.2	12.1	0.2
1990 characteristics, actual	41.7	0.2	4.2	0.1	8.2	0.1	36.8	0.2	9.2	0.1
1990 characteristics, 1985 model	47.7	0.2	4.4	0.1	10.2	0.1	26.6	0.2	11.1	0.1
1995 characteristics, actual	31.5	0.1	3.3	0.0	4.8	0.1	55.2	0.1	5.2	0.1
1995 characteristics, 1985 model	47.8	0.3	4.2	0.1	10.5	0.2	26.1	0.2	11.4	0.2
<b>20 years after award <sup>b</sup></b>										
1985 characteristics, actual	39.2	0.2	8.3	0.1	13.3	0.2	24.2	0.2	15.0	0.2
1990 characteristics, actual	38.0	0.2	7.7	0.1	10.5	0.1	32.3	0.2	11.4	0.1
1990 characteristics, 1985 model	40.0	0.2	8.3	0.1	13.7	0.2	24.0	0.2	13.9	0.2

SOURCE: Authors' calculations using SSA administrative records.

NOTES: DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

- a. Data for 1997 and 2000 are not included because 15 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).
- b. Data for 1995, 1997, and 2000 are not included because 20 years after award reflects a time horizon beyond the last observation point at the time the data were originally extracted (2010).

**Table A-2.****SSI and/or DI program participation and mortality experience of childhood SSI awardees aged 0–17 at award, by award cohort and years after award: Actual and 2000 model-predicted percentage distribution of awardees by outcome**

Award cohort, model	SSI only		DI only		Concurrent (SSI/DI)		Neither SSI nor DI, alive		Dead	
	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error	Percent	Standard error
<b>5 years after award</b>										
1985 characteristics, actual	67.3	0.2	0.7	0.0	2.4	0.1	22.8	0.2	6.9	0.1
1985 characteristics, 2000 model	60.6	0.2	0.6	0.0	1.8	0.0	33.5	0.2	3.6	0.1
1990 characteristics, actual	76.7	0.2	0.5	0.0	2.1	0.1	15.6	0.1	5.2	0.1
1990 characteristics, 2000 model	62.1	0.1	0.5	0.0	1.6	0.0	33.0	0.1	2.9	0.1
1995 characteristics, actual	51.8	0.1	0.4	0.0	1.2	0.0	43.8	0.1	2.8	0.0
1995 characteristics, 2000 model	60.8	0.1	0.4	0.0	1.3	0.0	34.9	0.1	2.6	0.0
1997 characteristics, actual	54.3	0.1	0.4	0.0	1.1	0.0	40.7	0.1	3.5	0.1
1997 characteristics, 2000 model	58.5	0.1	0.3	0.0	1.1	0.0	36.9	0.1	3.2	0.0
2000 characteristics, actual	59.9	0.1	0.3	0.0	1.1	0.0	35.8	0.1	2.9	0.0
<b>10 years after award</b>										
1985 characteristics, actual	60.6	0.2	2.0	0.1	5.9	0.1	22.0	0.2	9.6	0.1
1985 characteristics, 2000 model	48.6	0.2	1.9	0.0	3.2	0.1	41.1	0.2	5.1	0.1
1990 characteristics, actual	52.2	0.2	1.7	0.0	4.8	0.1	34.3	0.2	7.1	0.1
1990 characteristics, 2000 model	48.9	0.1	1.8	0.0	3.1	0.1	41.9	0.1	4.3	0.1
1995 characteristics, actual	37.8	0.1	1.4	0.0	3.1	0.0	53.7	0.1	3.9	0.0
1995 characteristics, 2000 model	47.4	0.1	1.5	0.0	2.8	0.0	44.6	0.1	3.7	0.0
1997 characteristics, actual	42.4	0.1	1.3	0.0	2.6	0.0	49.0	0.1	4.6	0.1
1997 characteristics, 2000 model	46.6	0.1	1.3	0.0	2.4	0.0	45.4	0.1	4.3	0.1
2000 characteristics, actual	46.7	0.1	1.4	0.0	2.5	0.0	45.5	0.1	4.0	0.1

SOURCE: Authors' calculations using SSA administrative records.

NOTES: Data for 15 and 20 years after award are not included because those years reflect a time horizon beyond the last observation point at the time the data were originally extracted (2010).

DI = Disability Insurance; SSA = Social Security Administration; SSI = Supplemental Security Income.

## Notes

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<sup>1</sup> In contrast to the means-tested SSI program, DI is a social insurance program with no means testing. To receive DI benefits, an individual must either become insured by acquiring a sufficient work history or be the dependent or survivor of someone who is insured. The definition of disability, however, is the same for adults in both programs.

<sup>2</sup> For adults, Rupp and Riley (2011) conducted a comprehensive analysis of SSI/DI interactions and established that SSI is often front-loaded, with SSI awardees transitioning to DI or concurrent status over time.

<sup>3</sup> Both programs use the same definition of categorical eligibility as disabled, but differ in other rules affecting exits and reentries. Most importantly, because of means testing, SSI benefits may be suspended as a result of fluctuations in family income and assets without change in categorical eligibility as disabled. Means testing also explains frequent returns to benefit eligibility status after a spell in nonreceipt status. In contrast, DI is conditioned on DI-insured status, which cannot be lost while categorically disabled. See Rupp and Riley (2011) for recent empirical differences in caseload dynamics of DI and SSI disability awardees among adults.

<sup>4</sup> Because our primary interest is in disability program participation that is due to an individual's own disability, we ignore DI receipt of youths younger than age 18. Childhood receipt of DI on another person's record does not require a disability determination; however, at age 18 (or by 19½ if still in school), a child receiving DI auxiliary benefits is required to undergo a medical determination for benefits. Additionally, although policy does not preclude children from receiving DI benefits as disabled workers before reaching age 18, the number who do so is very small. Also, for the majority of our analyses, we do not differentiate between DI benefits as a worker (based on the individual's own record) and DI benefits as a dependent (based on another person's record). See Research Question 5 in our Results section for more detail on disabled-worker and auxiliary DI benefit status of our sample members.

<sup>5</sup> The substantially higher average DI benefit is indicative of the potential to increase monthly benefits through transitioning to DI. Whether the transition to that program results only in a minor or more substantial increase in the monthly benefit stream is an important empirical issue for further study of SSI and DI benefit amounts of surviving childhood awardees during the working-age portion of the life cycle.

<sup>6</sup> Among adult DI awardees, the effective Medicare waiting period is 29 months; this is the result of the 5-month DI waiting period and the subsequent 24-month Medicare waiting period. Note that for former childhood SSI recipients transitioning from SSI to DI or to concurrent status, the 5-month DI waiting period for the vast majority of cases is irrelevant because those youths have accumulated well over 5 months as categorically disabled in the SSI program. The 24-month Medicare waiting period still applies, but of course those young adults are typically covered by Medicaid during that period.

<sup>7</sup> Exceptions to the 24-month Medicare waiting period include certain conditions, such as amyotrophic lateral sclerosis and end-stage renal disease, in addition to some instances of prior entitlement. Periodic suspension of cash benefits does count against the 24-month waiting period. Medicare coverage continues under periods of suspension of cash benefits for at least 93 months after the completion of a trial work period for persons whose disability benefits ceased because of SGA, but who continue to have a disabling impairment. Medicare rules for persons entitled to coverage because of disability are identical to the rules that apply to the elderly, including premium-free hospital insurance.

<sup>8</sup> Our results are generally robust to alternate groupings of impairments. For example, we experimented with using 3 broad impairment groups (mental, physical, and other), expanding the 7 impairment types used in this article into 9 groups (specifically separating out low birth weight and speech and language impediments into independent groups), and using the 18 impairment-type classification scheme that is applied in tabulations that appear in several SSA publications. None of these results were qualitatively different from those presented in this article.

<sup>9</sup> Diagnostic data before 1983 are generally unreliable, precluding regression modeling using the 1980 data. We do not include the 2010 award cohort in our regression analyses that use diagnostic mix, but provide that information in Table 1 and in the descriptive analyses that use aggregate time series.

<sup>10</sup> We hypothesize that in most cases, this arises when wage income is sufficiently sustained to earn DI-insured status, but generates relatively low DI benefits. Even assuming that these recipients continue to work at low wages on a sustained basis, their DI benefits plus earnings are sufficiently low to qualify them for SSI under the means test in these cases.

<sup>11</sup> Among the 17-year-old childhood SSI award cohort in 1980, about 24 percent died by age 48. By comparison, as of 2008, only about 4 percent of 17-year-olds in the United States were expected to die by age 48 (Arias 2012). For more information, see [http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61\\_03.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_03.pdf).

<sup>12</sup> For each observation point in the table, calendar year can be calculated by adding “award-cohort year” and “X,” which denotes year after award. X can take up the values of 1, 5, 10, 13, 20, 25 and 30 in the table depending on the number of year(s) after award listed in the spanners of each section. For example, for the 1980 award cohort in the top bank of the table under “1 year after award,” all observations refer to 1981 (=1980+1).

<sup>13</sup> In the chart, we distinguish the 1980, 1985, and 1990 award cohorts; all members from those cohorts entered the SSI program well before the 1996 welfare reform. The 1995 award cohort members entered the program right before the welfare reform, but their characteristics may have been affected by anticipatory effects of the welfare reform. More importantly, all award cohorts contain members who were subject to altered exit policies mandated by the welfare reform, albeit many from the 1980 and 1985 award cohorts exited the program rolls prior to 1996.

<sup>14</sup> The multivariate results confirm that age, sex, and diagnosis are all related to the percentage of individuals not participating in the disability programs in predictable ways for both years.

<sup>15</sup> The observed and predicted percentages in Appendix Tables A-1 and A-2 include both survivors and individuals who had died by the follow-up observation point. To express the percentages of awardees receiving neither SSI nor DI but who were alive among survivors, the numbers in the next-to-last column in both tables are multiplied by  $1/(1-\text{proportion dead})$ . For example, in the first row of both tables, nonparticipant survivors represented 22.8 percent of the award cohort. The proportion dead represented 6.9 percent of the award cohort. We calculate as follows:  $0.228/(1-0.069) = .245$  or 24.5 percent. Therefore, nonparticipants represented 24.5 percent of survivors 5 years after award for the 1985 award cohort. This method was used to derive the percentages presented in Chart 5.

<sup>16</sup> The intent of the legislation and the resulting regulations was to tighten the disability criteria. However, the implementation process also might have played some role. This would be consistent with a noticeable downward shift in nonparticipation trajectories as we move further from the era of welfare reform, when the sentiments for tightening the disability criteria were relatively strong.

<sup>17</sup> Auxiliary beneficiaries are individuals who receive DI benefits based on another person’s earnings record, such as a parent or spouse. Disabled auxiliaries can be either disabled widow(er)s (including disabled surviving divorced spouses), who must be aged 50 to the full retirement age, or disabled adult children, who must be aged 18 or older and have become disabled before reaching age 22 (in addition to other requirements). The definition of disability is the same for disabled auxiliary beneficiaries and disabled workers. There are also nondisabled auxiliary beneficiaries whom we do not consider in this analysis. Those include children younger than age 18 and certain spouses.

<sup>18</sup> Weathers and Bailey (2014) illustrate that employment and benefits counseling appear to play an important role in improving employment outcomes. Thus, explaining work incentives to beneficiaries, as advocated by Burkhauser and Daly (2011), also could be a promising component of potential future demonstrations that are designed to improve financial well-being through work. On the other hand, if the incentives do not affect beneficiary behavior under the status quo, as we argue, the cause could be a lack of knowledge or understanding resulting from the absence of targeted benefits counseling. Note that survey data suggest that the majority of youths aged 14–17 have never heard of SSA’s work incentives (Loprest and Wittenburg 2005).

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