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Health insurance regain after a spell of uninsurance: a longitudinal comparison of youth with and without disabilities transitioning into adulthood

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Abstract

Purpose—To examine insurance regain among youth with no, non-severe, and severe disabilities.

Methods—The data source for this study was the Survey of Income and Program Participation 2001–2004. We examined insurance regain among youth with no, non-severe, and severe disabilities between 15 and 25 using a longitudinal design. Kaplan-Meier survival functions provided estimates of uninsurance spell durations measured in waves, or 4-month intervals. We conducted a discrete time survival analysis adjusting for personal characteristics.

Results—This study includes 1310 youth who entered the SIPP with insurance and became uninsured. 985 youth (75%) regained insurance. Based on SIPP waves, median duration of uninsurance was 2 waves (between 5 and 8 months) for youth with severe disabilities and 3 waves (between 9 and 12 months) for youth with non-severe disability. Youth with non-severe disabilities had decreased odds of regaining health insurance compared to youth without disabilities (OR: .73; 95% CI: .57, .92; $p=.01$).

Conclusions—Youth with severe disabilities and youth without disabilities had similar odds of and durations to insurance regain. In contrast, youth with non-severe disabilities had lower odds of regaining insurance and experienced longer durations of uninsurance compared to peers without disabilities. We recommend additional research into the implications of Medicaid eligibility pathways and employment barriers for youth with non-severe disabilities.

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Introduction

Living without health insurance is common among youth, including youth with disabilities. The number of uninsured youth in the 19 to 29 year age group totaled 13.7 million in 2006, and 40% of the uninsured were under age 24 in 2004 [1,2]. One strategy for reducing uninsurance is to focus on covering certain segments of the population, such as children or persons with disabilities, through public programs like Medicaid [3,4]. Children also are afforded some security via their dependency status, thereby gaining coverage through parents' insurance.

However, youth who transition from adolescence to adulthood often become ineligible for both public and private coverage because of restrictions based on age and because of eligibility criteria related to disability [1]. Children and adolescents may have insurance coverage through public sources like Medicaid or receive assistance through states' Title V Children with Special Health Care Needs programs. As children and adolescents age, they may find that public systems provide benefits to adults with severe disability more readily than to adults without disabilities or with non-severe disabilities. For example, to receive Supplemental Security Income (SSI) and Medicaid, an adult must meet the Social Security Administration's definition of disability: "... the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" [5,6]. In contrast, adults with non-severe disabilities may experience some activity or work limitations, but may not qualify for public programs because they are still able to engage in substantial gainful activities.

After aging out of public programs or parents' private insurance plans, youth may also look for employment that offers private health insurance coverage. However, youth with both non-severe and severe disabilities may face barriers to gaining insurance through employers because of discrimination and work-related limitations [7,8]. Barriers to gaining insurance might also affect persons with non-apparent or invisible disabilities who experience difficulty securing assistance or accommodations because they are not seen as disabled and their impairments are not easily discernible [9].

Although many youth regularly experience losing insurance at transition ages, lack of coverage for even a short period of time may be more problematic for youth with disabilities. Periods of uninsurance can affect access to medical care for youth with disabilities who may need ongoing contact with the health care system, rate their health as fair to poor, and may require long term therapy [10–13].

Insurance among youth with disabilities in transition into adulthood has been examined by a few studies [10,14–16]. Our study extends prior work by examining regain of insurance after an episode of insurance loss among youth with disabilities in transition. Estimates of uninsurance may be overstated if regain is not taken into account. Further, the evidence on regain helps to show whether the insurance loss is permanent. This study addresses the following questions: Do youth who regain insurance have different personal characteristics than youth who do not regain insurance? What is the time to insurance regain among youth with and without disabilities who experience insurance loss? What is the association between disability status and insurance regain?

Methods

Data source and sample

The data source for this study was the Survey of Income and Program Participation (SIPP) 2001, sponsored by the U.S. Census Bureau. The 2001 SIPP was a prospective, longitudinal cohort survey conducted in nine waves. Each wave collected information about the previous 4-month period. For example, a SIPP interview conducted in April would also ask about a respondent's status in January, February, and March. The baseline year of the SIPP was 2001, and the SIPP followed individuals for up to 3 years.

The survey was designed as a multistage-stratified sample of the U.S. civilian non-institutionalized population. All household members age 15 and older were eligible to be interviewed, with proxy response permitted for household members not available at the time of interview. Face-to-face and telephone interviews collected data on insurance, source and amount of income, labor force participation, program participation and eligibility, general demographics, and disability status [17].

We used a longitudinal design to examine health insurance regain among youth with and without disabilities. Individuals were selected for this study if they provided information for assessing disability status and were between the ages of 15 and 25 at SIPP baseline. All members of this analysis had insurance coverage at SIPP baseline, but lost insurance during the SIPP follow-up period. We excluded youth who entered SIPP without insurance because we do not know when these youth became uninsured.

The study was approved by the University of Washington Human Subjects Division.

Measures

Uninsurance duration until insurance regain—The outcome of interest for this study is time until regaining insurance or right censoring. Right censoring describes a situation in which a participant remained uninsured through the end of the SIPP study, or a participant missed interviews or left the SIPP survey altogether.

Although the SIPP collects data about health insurance coverage on a monthly basis, we measure whether an event of insurance regain occurred during a wave, or a 4-month interval, because of seam problems in the SIPP data. For this study, a seam problem is an overestimate of insurance regain in the first month of a wave. For example, a participant may have been uninsured in January, but regained insurance in February and continued in an insured state for the rest of the year. However, when her SIPP interview occurs in April, she reports being insured in January, February, and March because of recall bias or conditioning to the interview pattern. Therefore, the seam effect affects accuracy of duration estimates as changes in insurance status occurring during a wave, or 4-month interval, appear to happen at the first month of the wave. [17].

Disability status—To create a single disability indicator, we used questions in the SIPP survey from Wave 5, Wave 8, and the labor section. The SIPP survey asked extensive series of questions in Waves 5 and 8 about having difficulty performing functional activities and activities of daily living. If respondents answered yes, they were then asked a series of questions about being unable to perform or needing help to perform the functional activities and activities of daily living. For example, a person who reported having difficulty using stairs would then be asked whether she was unable or required assistance to use stairs. The labor force section of the SIPP survey asked each month, "Do you have a physical, mental or other health condition that limits the kind or amount of work you can do?" If a respondent answered yes, then she was asked, "Does your health or condition prevent you from working at a job or business?"

Our final disability indicator was a set of dummy variables for having no disability, non-severe disability, and severe disability. A person without disability reported no activity or work limitations. Persons with non-severe disabilities had difficulty with functional activities and activities of daily living or reported having conditions that limited work for at least twelve months. Persons with severe disability were unable to perform or required assistance to perform functional activities and activities of daily living or reported having conditions that prevented work for at least twelve months.

Personal Characteristics—Time invariant factors include gender, race, and Hispanic ethnicity.

Time-varying covariates include age, poverty, and education level. Poverty status was based on family income and shows whether individuals: 1) lived above 100% of federal poverty level (FPL); or 2) lived at or below 100% FPL. Education level was categorized as: 1) 12th grade or below; 2) high school graduate or GED; or 3) some college or more. The SIPP measured time-varying covariates at monthly intervals, and we use the value recorded in the first month of each wave to represent the wave.

Statistical Analysis

We used survival analysis to estimate the duration of uninsurance spells. The Kaplan-Meier survival functions provided descriptive estimates of uninsurance spell durations and median spell lengths.

We conducted a discrete time survival analysis to calculate the association between disability status and insurance regain. This maximum likelihood technique allows each study sample member to contribute different amounts of time to the dataset and accommodates both time-varying and invariant factors related to insurance regain [18]. The unit of analysis for this study was a participant's first spell of uninsurance. The dataset was in the person-period form in which a person had multiple records for each wave (4-month interval) of observation until she regained health insurance or became right censored. We chose to measure time with the wave rather than the month because of evidence of seam problems in the SIPP. Adjustment variables were gender, race, ethnicity, age, poverty status, and education level.

Analyses were conducted using Stata 10.0 (StataCorp, College Station, TX).

Results

Sample characteristics

This study includes 1310 youth who entered the SIPP with insurance and subsequently lost insurance. The youth were between the ages of 15 and 27 when they first lost insurance and had an average age of 20.7 years. Nine hundred and eighty-five youth (75%) regained insurance. Table 1 shows the personal characteristics of study participants, and youth who regained health insurance were more frequently without disabilities.

Uninsurance spells

Our study examined 1310 spells of uninsurance, which ranged in duration from 1 to 9 waves. Table 2 describes uninsurance spells by disability status. Of the 975 youth without disabilities, 751 (77%) regained insurance. The median duration of uninsurance spells for youth without disabilities was 2 waves. The incidence rate of regaining insurance for youth without disabilities was .29 based on 2573 person-waves of follow-up. One hundred fourteen out of 175 youth with non-severe disabilities (65%) regained insurance. The median duration of uninsurance for this group was 3 waves. After 488 person-waves of follow-up, the incidence

rate of regain was .23 for youth with non-severe disabilities. Finally, 120 out of the 160 youth with severe disabilities (75%) regained insurance. The median duration was 2 waves, and the incidence of regain based on 403 person-waves was .30 for youths with severe disabilities.

Figure 1 shows a Kaplan-Meier curve depicting the proportion of uninsured youth who regained health insurance over time by disability status.

Associations with Insurance Regain

Table 3 shows three models showing associations with insurance regain. Model 1 includes only time as dummy variables and shows that the odds of regaining insurance rise through wave 2, decrease through wave 6, and generally plateau through wave 8. We then add disability into Model 2 and unadjusted estimates indicate that youth with non-severe disabilities are at decreased odds of regaining insurance compared to youth without disabilities. However, youth with severe disabilities and youth without disabilities have similar odds of regaining health insurance. Model 3 provides the association between insurance regain and disability after adjusting for race, ethnicity, gender, poverty, age, and education level. Youth with non-severe disabilities have significantly decreased odds of regaining health insurance compared to youth without disabilities (OR: .73; 95% CI: .57, .92; $p=.01$).

Table 4 describes the type of insurance that youth regained. Among youth without disabilities, 59% regained private insurance, 18% regained public insurance, and 23% remained uninsured. Among youth with non-severe disabilities, 38% regained private insurance, 27% regained public insurance, and 35% remained uninsured. Among youth with severe disabilities, 37% regained private insurance, 38% regained public insurance, and 25% remained uninsured.

Discussion

Youth with severe disabilities and youth without disabilities have similar durations of uninsurance and odds of insurance regain. In contrast, youth with non-severe disabilities remain uninsured longer and have approximately 30% lower odds of regaining insurance compared to peers without disabilities. This may be because only youth with severe disabilities qualify for insurance coverage through public programs. Pathways intended to provide Medicaid coverage to persons with severe disabilities include enrollment following eligibility for cash assistance through the Supplemental Security Income (SSI) program, Medically Needy Programs, home and community-based waivers, and the Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option [4–6,19,20].

Our finding also may be due partly to work programs directed toward persons with severe disabilities. For example, persons with severe disabilities may be eligible to receive supported employment services, which the Department of Labor defines as facilitating “competitive work in integrated work settings for individuals with the most severe disabilities...for whom competitive employment has not traditionally occurred, and who, because of the nature and severity of their disability, need ongoing support services in order to perform their job” [21]. In some cases, the employer may provide some health benefits for employees who are participating in supported employment.

Our study shows that 35% of youth with non-severe disabilities remain uninsured compared to approximately 25% of peers without disabilities or with severe disabilities. (Table 4) This 10% difference may reflect two barriers to regaining insurance encountered by youth with non-severe disabilities. First, these youth may not have qualified for public benefits. Second, they may have a lower likelihood of regaining insurance because of challenges with transitioning into postsecondary independence and work that provides health insurance [22,23]. A study with young women with learning disabilities pointed to flaws in transition processes that left

youth without accurate information about applying for college, receiving services, or future opportunities [24]. Further, workplaces continue to demonstrate reluctance in hiring, retaining, and promoting persons with disabilities despite passage of the Americans with Disabilities Act in 1990 [7,8,25–27].

Although persons with disabilities are generally at risk for experiencing hardship, we hypothesize that hardship has a specific effect on the insurance status of persons with non-severe disabilities. She and Livermore define hardship as an inability to meet expenses, to pay bills, to obtain needed medical and dental care, and to achieve food security [28]. Youth with non-severe disabilities may find that they are ineligible for Medicaid and cash assistance through SSI, are ineligible for work transition programs, and are experiencing challenges with entering and staying part of the workforce. As a result, persons with non-severe disabilities experiencing hardship may feel compelled to use their limited resources for rent, gas, and food rather than for purchasing health insurance.

The majority of youth in our study, particularly youth with non-severe disabilities, experienced medium to long durations of uninsurance. Median duration of uninsurance was 2 waves (between 5 and 8 months) for youth with severe disabilities and 3 waves (between 9 and 12 months) for youth with non-severe disability. In other words, half of youth with severe disabilities were still uninsured after 2 waves, and half of youth with severe disabilities were still uninsured after 3 waves. Likely consequences to these gaps in coverage include: reduced access to a usual source of care, delayed care, unmet medical or prescription drug need, lowered likelihood of visiting a health provider, and increased likelihood of being burdened by medical debt [1,29–31].

For both youth with and without disabilities, the odds of regaining insurance increase through wave 2 and then decrease through wave 6 showing that the longer youth go without health insurance, the less likely they will regain it. Therefore, a sensible strategy for supporting youth in transition includes alerting youth to health insurance sources and reenrolling youth quickly if they lose insurance. States could increase awareness of insurance programs, like Medicaid Buy-In, for persons with disabilities through communication campaigns, a strategy employed by states for State Children's Health Insurance Program (SCHIP) enrollment [32–34]. Enrollment procedures could be streamlined via ties to a youth's Individualized Education Program (IEP). This would be similar to the "express lane eligibility" used by some states to enroll into Medicaid the children who participate in free or reduced school lunch programs [35].

Youth health may also explain the decreasing odds of insurance regain over time. Youth who experience longer durations of uninsurance may be healthier than those who regain the insurance quickly. The healthy youth may not find value in maintaining continuous coverage and do not pursue reenrollment. Strategies for reenrolling youth should consider youth attitudes toward and beliefs about health insurance.

Alternatively, some youth may lose health insurance because of administrative barriers, but they regain the insurance as soon as they detect and solve the problem. However, those who lose insurance due to true loss of eligibility do not regain their insurance. The implications of this finding are to examine the unintended effects of eligibility criteria as well as to prevent insurance loss altogether.

Five policy options have been outlined as possible strategies to improve health insurance coverage among young adults: 1) requiring employers to allow parents to cover their children up to age 26; 2) allowing Medicaid or SCHIP to cover more low income young adults; 3) requiring insurance coverage for college students; 4) providing tax credits to individuals for purchasing coverage in the non-group market; and 5) mandating all young adults obtain

coverage [1,36]. However, four of these options offer only limited benefit to youth with disabilities. Allowing parental coverage to age 26 may only postpone or delay transition challenges. Mandating coverage for college students only applies to youth who are college bound, and rates of postsecondary school attendance are significantly lower among youth with disabilities compared to peers in the general population [37]. Even with tax credits, non-group insurance premiums and out of pocket spending may be unaffordable for persons with health needs [38]. Mandating coverage assumes that an existing insurance source will offer and provide affordable coverage.

Therefore, we suggest that policy makers support Medicaid or SCHIP expansion because this strategy may be the most meaningful for youth with disabilities. Expanding public programs may help to increase the odds that youth with non-severe disabilities regain insurance and spend less time in episodes of uninsurance by offering an insurance source outside of the employer-based system. This may be an important support to youth who do not proceed through college into full-time work in the traditional 4 or 6 years.

This study has several limitations. First, our disability indicator is similar to the definition used by the US Census Bureau, but the indicator is not a validated or reliable measure of disability [39]. Further, the SIPP does not repeat the survey questions related to disability in every wave, but only in Waves 5 and 8. As a result, subjects' disability status may be constant or it may be changing through the period of the SIPP study. Although the SIPP questions related to disability have been criticized, we are not aware of any other data source that includes both children and young adults in transition ages, a longitudinal design, and insurance coverage questions. Therefore, we recommend that future studies include a more robust disability assessment instrument that is regularly measured over time. Disability may then be incorporated as a time-varying covariate into models to estimate more accurately the association between disability and insurance regain.

Second, we examine only the first episode of uninsurance and are unable to make inferences about the time to insurance regain following subsequent episodes of uninsurance. Third, the analysis does not include weights and may not be generalizable to the U.S. population. Fourth, the time scale that we use, a wave, does not provide the most refined or intuitive estimate of time to insurance regain. Even though the SIPP asks about insurance on a monthly basis, monthly estimates would probably have been biased because of a seam effect. To address seam problems, we suggest the strategy studied by Rips et al for surveys to place repeated items in different parts of the questionnaire and ask questions using backward recall [40].

In addition to designing studies that evaluate disability over time and applying a different method for asking questions, future studies could examine the subset of individuals who go years without regaining insurance. Haley and Zuckerman note that policymakers need "to consider approaches that meet the needs of both the short- and long-term uninsured..." [29]. Researchers can also conduct additional quantitative and qualitative studies on the environmental or structural factors that may cause youth with non-severe disabilities to have lower risk of regaining insurance and to remain in uninsurance longer.

Conclusion

This study shows differences between youth with and without disabilities in insurance regain. Youth with severe disabilities in this study have similar odds of regaining insurance over time and have similar durations of uninsurance as peers without disabilities. This may be related to SSI and Medicaid eligibility pathways and employment programs targeting persons with severe disability. In contrast, youth with non-severe disability have lower odds of regaining insurance and experience longer durations of uninsurance compared to youth without disabilities. Youth

with non-severe disabilities may not be eligible for public benefits or qualify for work programs. Economic hardship and workplace discrimination also may act as barriers to obtaining health insurance among youth with non-severe disabilities. Time spent without insurance is likely to decrease youth's access to timely care and to place youth at risk for meeting health plans' preexisting condition clauses. Our finding that the odds of regaining insurance peak and then decline suggests the importance of acting quickly to reenroll youth into coverage.

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Figure 1.
Kaplan-Meier survival estimates for regaining health insurance, by disability status (n=1310)

Table 1

Among Youth Who Lost Health Insurance, Characteristics of Youth Who Did Not Versus Did Regain Insurance

	Did not regain health insurance n=325 number (%)	Regained health insurance n=985 number (%)
Disability status *		
Severe disability	40 (25)	120 (75)
Non-severe disability	61 (35)	114 (65)
No disability	224 (23)	751 (77)
Gender		
Female	157 (23)	521 (77)
Male	168 (27)	464 (73)
Race		
Black, Native American, Alaska Native, Asian, Pacific Islander	76 (26)	218 (74)
White	249 (25)	767 (75)
Ethnicity		
Hispanic	51 (26)	148 (74)
Non-Hispanic	274 (25)	837 (75)
Poverty status at time of insurance loss		
At or below 100% FPL	73 (21)	272 (79)
Above 100% FPL	252 (26)	713 (74)
Education status at time of insurance loss		
12th grade or below	97 (25)	288 (75)
High school graduate or GED	122 (28)	313 (72)
Some college or more	106 (22)	384 (78)

*
p<.05, Pearson chi²

Table 2

Description of Uninsurance Spells, By Disability Status

	Number of uninsured youth	Number who regained insurance	Follow-up time (person-waves)	Incidence rate (number who regained/person-waves)	Median duration of uninsured spell	
					waves	months
No disability	975	751	2573	0.29	2	5 to 8 months
Non-severe disability	175	114	488	0.23	3	9 to 12 months
Severe disability	160	120	403	0.30	2	5 to 8 months
All	1310	985	3464	0.28	2	5 to 8 months

Table 3

Personal Characteristics Associated with Youth Regaining Insurance

	Model 1		Model 2		Model 3	
	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)
Time						
Wave 1	0.23	0.20	0.23	0.20	0.20	0.11
Wave 2	0.87	0.77	0.91	0.79	0.82	0.43
Wave 3	0.46	0.38	0.49	0.40	0.44	0.22
Wave 4	0.30	0.23	0.32	0.24	0.29	0.14
Wave 5	0.26	0.18	0.27	0.19	0.25	0.12
Wave 6	0.16	0.10	0.17	0.10	0.16	0.07
Wave 7	0.19	0.10	0.20	0.10	0.19	0.07
Wave 8	0.19	0.07	0.20	0.07	0.21	0.06
Disability Status						
No disability			Ref		Ref	
Non-severe disability			0.72	0.57	0.73	0.57
Severe disability			1.00	0.79	1.06	0.84
Race						
White					Ref	
Black, Native American, Alaska Native, Asian, Pacific Islander					0.78	0.66
Ethnicity						
Non-Hispanic					Ref	
Hispanic					0.74	0.60
Gender						
Male					Ref	
Female					1.17	1.00
Poverty Level						
Above poverty					Ref	
At or below poverty					.99	0.83
						1.19

	Model 1		Model 2		Model 3	
	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)
Age					1.00	0.96 1.02
Education Level						
12th grade or below					Ref	
High school graduate or GED					1.09	0.88 1.34
Some college or more					1.43	1.15 1.78

Logistic Regression Odds Ratios (OR; n=1310, n insurance regain events = 985)

Table 4

Type of Insurance Regained by Youth, by Disability Status

	Regained private health insurance n=702 number (%)	Regained public health insurance n=283 number (%)	Remained uninsured n=325 number(%)
Disability status *			
Severe disability	59 (37)	61 (38)	40 (25)
Non-severe disability	67 (38)	47 (27)	61 (35)
No disability	576 (59)	175 (18)	224 (23)

*
p<.001, Pearson chi²