Access to Care

Health-Related Unmet Needs of Supplemental Security Income Youth after the Age-18 Redetermination

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Objective. Young adults who exit Supplemental Security Income (SSI) after their age-18 eligibility redetermination may have greater health-related unmet needs than those who remain on SSI. The objective of this paper is to determine the magnitude and causes of this gap.

Data Sources. Uses the 2001–2002 National Survey of SSI Children and Families, a nationally representative survey of SSI youth.

Study Design. Self-reported unmet medical, dental, and prescription drug needs of 869 individuals ages 19–23 who have had their SSI eligibility redetermined are compared. In addition to raw differences in unmet needs, logistic regressions are used to determine the sources of these differences.

Principal Findings. Young adults who exit SSI are almost twice as likely to have health-related unmet needs subsequent to their exit as those who remain on SSI after the age-18 redetermination. Access to care, particularly insurance coverage (either Medicaid or non-Medicaid), accounts for much of the difference between these two groups; measures of health status do not explain much of the difference.

Conclusion. Policies addressing access to health care are likely to be more successful in addressing unmet needs than policies focused on disability-specific issues in health for youth who lose access to SSI after their age-18 redetermination.

Key Words. Supplemental Security Income (SSI), unmet health needs, youth

To be eligible for the Supplemental Security Income (SSI) program, a means-tested income support program for the blind, disabled, and elderly administered by the Social Security Administration (SSA), children must have a medically determinable physical or mental impairment that is expected to last (or has lasted) at least 12 continuous months or to result in death and results in marked and severe functional limitations and have sufficiently low income and assets. At age 18, the medical eligibility of all youth is redetermined under adult program rules, which requires them to have an impairment that prevents

them from performing substantial gainful activity (defined as work activity of more than U.S.\$980 per month in 2009). About one-third of these age-18 redeterminations result in a cessation of SSI eligibility each year (SSA 2009).¹

Although these young adults do not meet SSA's adult disability criteria, many of them may still require significant amounts of medical care to address their medical condition. Lack of appropriate health care may lead to health complications or deterioration of their medical condition, which could result in a transition back to SSI. In addition to the heightened risk of having an unmet need due to their condition, many of these young adults are also at an increased risk of having an unmet need because they also lose Medicaid coverage when they are determined to be medically ineligible for SSI because SSI eligibility also determines Medicaid eligibility in most states. Whether these young adults are actually receiving less care than needed and to what extent this may be due to their exit from SSI is unknown.

While not having insurance is common among young adults with and without disabilities (Fishman 2001; Callahan and Cooper 2006, 2007), former SSI children are more likely to lack health insurance at ages 19–23 than their peers who remained on SSI (Loprest and Wittenburg 2007). The lack of insurance for young adults with disabilities may result in limited access to preventive or required care, precluding these young adults from obtaining employment or becoming economically self-sufficient.² Alternatively, young adults who exit SSI are relatively healthier individuals and thus may have fewer needs than their peers who remain on SSI.

Additionally, few youth with disabilities receive help with health services, such as the coordination of care between and within pediatric and adult services, which would smooth their transition into adulthood (Scal and Ireland 2005). Even young adults remaining on SSI may require assistance because they receive a different package of health care services as an adult (Williams and Tolbert 2007). More important for young adults who exit SSI, even short periods of time without health insurance have been shown to impact health outcomes (Olson, Tang, and Newacheck 2005; Cummings et al. 2009). Changes in insurance coverage have also been shown to delay receipt of, or reduce access to, care (Burstin et al. 1998/1999).

Because few studies have explored the relationship between SSI's age-18 redetermination and the unmet health needs of transition-age youth, this study

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addresses the following questions: Are young adults who leave SSI after the age-18 redetermination more likely to have health-related unmet needs than those who remain on SSI? If so, does health status or lack of insurance explain this difference?

METHODS

Theoretical Framework

The purpose of this study is to examine the extent of unmet medical needs in young adults who remained on SSI versus those who exited SSI after their age-18 redetermination. This analysis is based on a framework developed by Aday and Andersen (1974). This framework describes how health policy can affect both the health care system and the characteristics of the population at risk to change health care utilization. Newacheck et al. (2000) provide a typical application that the current study follows closely.

Population characteristics are summarized by three broad domains. The first domain is the need for health care, which is the condition that causes health care use. One can hypothesize that those who remain on SSI presumably have more severe health conditions and have greater health care needs compared with those who have exited SSI.³ However, because of greater health care access, young adults on SSI may actually have lower *unmet* needs. Thus, the second domain, “enabling” in the Aday–Andersen model and describing the ability to receive health care (measured primarily by health insurance), should explain much of the difference between the unmet health needs between those on and off SSI. The third domain includes “predisposing” characteristics, which includes primarily demographic characteristics that increase an individual’s underlying “propensity” to use care.

Data

The data used are from the National Survey of SSI Children and Families (NSCF) restricted-use data file. The NSCF is a nationally representative survey of noninstitutionalized SSI children and young adults, conducted by Mathematica Policy Research Inc. The NSCF sample was drawn from administrative records to include several specific cohorts. One of these groups is a cohort of recipients who received SSI in 1996 and who provide the study base for this study. Data collection occurred for all cohorts between July 2001 and July 2002 through in-person and telephone interviews. The data contain information on the health, employment, income, and demographic characteristics of youth at the time of the survey. Of the 11,971 in the eligible sample, only 9,242

individuals were contacted; of these, 516 were later determined to be ineligible for the survey. This led to an overall unweighted response rate of about 77 percent. For more information on the NSCF, see Gillcrest and Edson (2004) and Davies and Rupp (2005/2006).

From this sample, I limit the analysis on respondents who were ages 19–23 at the time of the survey and who had an age-18 redetermination (based on a match with SSA's administrative records),⁴ leaving 869 individuals for this analysis. This group is representative of the youth who aged out of child-based SSI payments between 1996 and 2002. Although there have been some changes in this population over time, their observed characteristics are generally constant (Hemmeter and Gilby 2009) and the results can likely be generalized to current population.

Individuals are counted as being “on” SSI if they were receiving SSI in the month before the survey and remained on SSI as a result of their age-18 redetermination. They are considered “off” SSI if they were not receiving SSI in the month before the survey and their benefits were ceased due to their age-18 redetermination.⁵

Analyses

Descriptive statistics were calculated to generate the demographic profiles and differences in the levels of unmet health care needs between young adults on and off SSI. Next, logistic regressions of the presence of an unmet need were run controlling for SSI status and variables measuring the individual's need, enabling, and predisposing characteristics. These factors are sequentially included in the model to measure their impact on the effect of SSI participation.

All analyses were performed using *STATA* 11 and use balanced repeated replication weights to control for the complex survey methodology of the NSCF. Results are presented as marginal effects for ease of interpretation. Marginal effects are essentially the average change in the outcome, overall observations, when the independent variable changes by one unit, all else equal, and are interpreted as percentage point changes. See Bartus (2005) for more information on how marginal effects are calculated. The underlying odds ratios from the logistic regressions are available upon request.

Variables

The dependent variables in this study are four measures of unmet needs: whether the individual had an unmet medical care need (e.g., doctor), an unmet prescription drug need, an unmet dental need, or any of these three

health-related unmet needs. These unmet needs are determined by survey questions asking whether the individual delayed or went without a needed service in the past 12 months.⁶ It should be noted that dental needs are slightly different from other medical needs in that all adults are recommended to see a dentist at least every 6 months, increasing the likelihood of an unmet dental need regardless of other characteristics. Additionally, insurance for dental care typically includes higher copayments (Sintonen and Linnosmaa 2000).

As noted previously, there are three broad categories of variables used as independent variables to explain the presence of unmet needs. An individual's "need" for health care is measured by the following variables: self-reported health status (poor/fair/good/very good or excellent);⁷ disability severity (high/moderate/low or none);⁸ and type of disability (mental retardation/behavior and other mental disorders/sensory and systemic disorders/other disability).⁹

"Enabling" characteristics were captured through measures of fiscal and social support: insurance status (any Medicaid/non-Medicaid-only/uninsured);¹⁰ household income relative to the poverty line (less than or equal to poverty line/101–150 percent of poverty line/> 150 percent of poverty line); employed status; living situation (living with a single parent/living with two parents/living with a guardian/other); and SSI status. Individuals living with others, particularly their parents, may have greater transportation options or family income that may increase their ability to receive care. "Predisposing" characteristics include gender, race (white/non-white), and ethnicity (Hispanic/non-Hispanic). To control for possible bias when individuals did not answer for themselves, an indicator for when a proxy respondent was used is also included in the model.¹¹ It should be noted that some variables may fit into more than one category.

RESULTS

Characteristics of the Sample

About 20 percent of the sample lost access to SSI after their age-18 redetermination (Table 1). Those off SSI report having an unmet health care need almost twice as frequently as those who remain on SSI. Almost 60 percent of young adults off SSI report having any unmet need compared with 32 percent of young adults on SSI. For medical needs, 36 percent of former SSI recipients report an unmet need compared with only 12 percent of continuing recipients. There is a 12 percentage point difference in the prevalence of unmet dental needs between those off and on SSI after the age-18 redetermination and a 30 percentage point difference in the prevalence of unmet prescription drug needs.

Table 1: SSI Status, Presence of an Unmet Need, Insurance Type, and Health Characteristics of Young Adults Who Were on SSI as a Child, by SSI Status after Age 18

	<i>All</i>		<i>Off SSI</i>		<i>On SSI</i>		<i>Difference</i>	<i>p-Value</i>
	<i>%</i>	<i>SE</i>	<i>%</i>	<i>SE</i>	<i>%</i>	<i>SE</i>		
Unmet needs								
Any unmet need	37.54	1.55	58.92	3.42	31.90	1.62	0.27	.00
Medical need	16.64	1.03	36.02	2.95	11.53	0.92	0.24	.00
Dental need	28.67	1.35	38.33	2.50	26.13	1.58	0.12	.00
Prescription drug need	11.82	0.76	35.64	2.84	5.54	0.52	0.30	.00
Enabling factors								
SSI status								
On SSI	79.15	1.23	0.00	0.00	100.00	0.00	1.00	
Insurance type								
Medicaid	81.33	1.02	24.65	2.58	96.26	0.56	-0.72	.00
Non-Medicaid	4.23	0.48	14.00	2.06	1.65	0.20	0.12	
Uninsured	14.44	0.95	61.35	2.69	2.09	0.53	0.59	
Household income relative to poverty line								
Less than or equal to poverty line	52.71	1.71	63.14	2.51	49.97	1.79	0.13	.00
Between 101% and 150% of poverty line	23.36	1.13	15.38	1.48	25.47	1.31	-0.10	
> 150% of poverty line	23.92	1.41	21.48	2.58	24.57	1.53	-0.03	
Employment								
Employed	18.66	1.08	36.03	3.09	14.09	1.15	0.22	.00
Living situation								
Two parents	24.15	1.27	12.84	1.69	27.13	1.48	-0.14	.00
Single parent	44.38	1.43	51.35	3.33	42.54	1.53	0.09	
Guardian	10.60	0.89	4.53	0.79	12.20	0.97	-0.08	
Other (including on own)	20.75	1.01	30.93	3.15	18.06	1.02	0.13	
Need factors								
Health status								
Poor	12.74	0.84	13.43	1.94	12.56	1.02	0.01	.42

continued

Table 1. *Continued*

	<i>All</i>		<i>Off SSI</i>		<i>On SSI</i>		<i>Difference</i>	<i>p-Value</i>
	%	SE	%	SE	%	SE		
Fair	27.03	1.07	29.47	2.56	26.39	1.32	0.03	
Good	41.51	1.28	41.50	2.88	41.51	1.54	0.00	
Very good or excellent	18.71	1.04	15.60	1.88	19.54	1.15	-0.04	
Severity of disability								
High severity	50.92	1.45	42.85	2.93	53.04	1.56	-0.10	.00
Moderate severity	32.58	1.35	24.79	2.21	34.63	1.72	-0.10	
Low severity/none	16.50	1.04	32.35	2.69	12.33	0.97	0.20	
Disability type								
Mental retardation	54.88	1.35	38.94	2.58	59.08	1.41	-0.20	.00
Behavioral and other mental disorders	17.65	0.95	27.34	2.40	15.10	0.82	0.12	
Sensory/systemic disorders	12.57	0.92	4.17	0.59	14.79	1.15	-0.11	
Other disability	14.89	0.99	29.55	2.74	11.03	1.13	0.19	
Predisposing factors								
Gender								
Male	55.92	1.25	66.98	2.94	53.01	1.45	0.14	.00
Race								
White	49.34	1.93	45.48	3.78	50.36	2.10	-0.05	.23
Ethnicity								
Hispanic	14.67	1.30	14.87	2.70	14.62	1.35	0.00	.93
Proxy status								
Proxy respondent	80.42	1.06	68.66	2.93	83.52	1.04	-0.15	.00
Observations (unweighted)	869		163		706			
Observations (weighted)	129,836	3,127	27,071	1,700	102,765	3,002		

Note. Standard errors (SE) are Balanced Repeated Replicate standard errors.

SSI, Supplemental Security Income.

Source. Author's calculations from the National Survey of SSI Children and Families.

These groups have significant differences in health insurance and disability type and severity. Consistent with the objective of the age-18 redetermination process to end SSI receipt of youth who are not medically eligible as an adult, young adults who are off SSI are less likely to report having a severe disability. Additionally, they are less likely to have sensory or systemic disorders or mental retardation, disability types which are more likely to directly correspond with specific adult disability listings.

Over 80 percent of the sample is covered by Medicaid and 14 percent is uninsured. As would be expected given the link between SSI receipt and Medicaid, 96 percent of young adults remaining on SSI are covered by Medicaid compared with only 25 percent of those off SSI. Only 2 percent of young adults on SSI are uninsured compared with 61 percent of those off SSI. Similarly, only 2 percent of young adults on SSI have only non-Medicaid insurance compared with 14 percent of young adults off SSI.

There are also large differences in other characteristics by SSI status. Consistent with Loprest and Wittenburg (2007) and Hemmeter, Kauff, and Wittenburg (2009), young adults off SSI are much more likely to be employed than those on SSI. Young adults off SSI are also more likely to be living in poverty and be male than those on SSI; they are less likely to live with two parents or a guardian. By far, most of the sample's survey responses come from a proxy. More of those on SSI required a proxy response than those off SSI, consistent with the higher level of high severity disabilities among this group.

Logistic Regression Results

The results from regression models to determine if changes in unmet need were due to health status or insurance status in the different SSI groups are shown in Table 2. Different variables are sequentially added into the regressions to compare what effect they have on the SSI status coefficient. If a variable reduces the SSI coefficient, then it can be argued that it is confounding the effect of SSI receipt and it suggests that it may explain a larger part of the difference between the two groups. I also present the results of the regressions including all the variables in a single model, showing how, all else equal, these variables affect the likelihood of an unmet need (Table 3). Only the SSI, health, and insurance variables are discussed below.

SSI Status

The logistic regressions illustrate how controlling for insurance reduces the impact of SSI status, whereas controlling for health status does not

Table 2: Marginal Effects from Logistic Regressions on Presence of Unmet Needs

	(1)	(2)	(3)	(4)	(5)
Panel A: Any unmet need					
Effect of being off SSI on any unmet needs	0.27*** 0.04	0.29*** 0.03	0.01 0.04	-0.02 0.04	-0.04 0.04
Panel B: Unmet medical need					
Effect of being off SSI on unmet medical needs	0.24*** 0.03	0.26*** 0.03	0.00 0.02	-0.02 0.02	-0.02 0.02
Panel C: Unmet dental need					
Effect of being off SSI on unmet dental needs	0.12*** 0.03	0.13*** 0.03	-0.05 0.03	-0.07*** 0.03	-0.09*** 0.03
Panel D: Unmet prescription drug need					
Effect of being off SSI on unmet prescription drug needs	0.30*** 0.03	0.34*** 0.03	0.08*** 0.03	0.10*** 0.04	0.09*** 0.02
Model includes					
Health variables	N	Y	N	Y	Y
Insurance variables	N	N	Y	Y	Y
Demographic, ability-to-pay for care, and proxy variables	N	N	N	N	Y

Notes: Balanced Repeated Replicate standard errors are beneath the marginal effects.

Health variables: health status (fair/good/very good or excellent versus poor); disability severity (high/moderate versus low or none); disability (behavioral and other mental disorders/sensory and systemic disorders/other versus mental retardation).

Insurance variables: uninsured/non-Medicaid only versus Medicaid.

Demographic and ability-to-pay variables: male; race (non-white versus white); Hispanic; employed; living arrangement (with single parent/with guardian/other versus with two parents); proxy response; poverty level (101%-150%/over 150% versus at or below poverty level).

Full regression results available upon request.

***Significant at $p \leq .05$;

***Significant at $p \leq .01$.

SSI, Supplemental Security Income.

Source: Author's calculations from the National Survey of SSI Children and Families.

Table 3: Marginal Effects from Logistic Regressions on Presence of Unmet Needs

<i>Variables</i>	<i>Any Unmet Need</i>	<i>Unmet Medical Need</i>	<i>Unmet Dental Need</i>	<i>Unmet Prescription Drug Need</i>
Enabling factors				
SSI status (reference = on SSI)				
Off SSI	− 0.04	− 0.02	− 0.09***	0.09***
	0.04	0.02	0.03	0.02
Health insurance (reference = Medicaid)				
Uninsured	0.48***	0.42***	0.33***	0.27***
	0.03	0.03	0.04	0.03
Non-Medicaid	0.00	0.05	− 0.02	0.07**
	0.07	0.04	0.07	0.03
Poverty status				
Between 101% and 150% to poverty line	− 0.03	− 0.02	0.01	− 0.06***
	0.04	0.02	0.04	0.01
> 150% of poverty line	0.04	0.09***	0.02	− 0.06***
	0.04	0.03	0.04	0.01
Employed status (reference = not employed)				
Employed	− 0.02	0.07***	− 0.02	0.00
	0.04	0.02	0.04	0.02
Living arrangement (reference = two parents)				
Single parent	0.05	0.05*	0.02	0.00
	0.03	0.03	0.03	0.01
Guardian	− 0.12***	− 0.01	− 0.19***	− 0.06***
	0.04	0.03	0.03	0.02
Other (including on own)	− 0.11**	0.01	− 0.13***	− 0.03
	0.04	0.03	0.04	0.02
Need factors				
Health status (reference = poor)				
Fair	− 0.12***	− 0.06*	− 0.07**	− 0.05***
	0.03	0.03	0.03	0.02
Good	− 0.07**	− 0.02	− 0.06*	− 0.09***
	0.03	0.03	0.03	0.02
Very good or excellent	− 0.14***	− 0.11***	− 0.07**	− 0.10***
	0.04	0.02	0.03	0.02
Disability severity (reference = low/none)				
High severity	0.13***	0.16***	0.12***	0.07***
	0.03	0.03	0.03	0.02
Moderate severity	0.03	0.11***	0.05	0.09***
	0.03	0.04	0.04	0.02
Disability (reference = mental retardation)				
	0.02	0.04**	0.02	0.04**
	0.03	0.02	0.03	0.01

continued

Table 3. *Continued*

<i>Variables</i>	<i>Any Unmet Need</i>	<i>Unmet Medical Need</i>	<i>Unmet Dental Need</i>	<i>Unmet Prescription Drug Need</i>
Behavioral and other mental disorders				
Sensory/ systemic disorders	0.01 0.04	− 0.03 0.03	0.02 0.04	− 0.02 0.02
Other disability	0.05 0.04	0.05 0.03	0.08** 0.04	− 0.02 0.01
Predisposing factors				
Gender (reference = female)				
Male	− 0.02 0.03	− 0.03* 0.02	0.00 0.03	− 0.04*** 0.01
Race (reference = white)				
Non-white	− 0.04 0.03	− 0.05*** 0.02	0.01 0.03	− 0.04*** 0.01
Ethnicity (reference = non-Hispanic)				
Hispanic	− 0.10*** 0.03	− 0.01 0.03	− 0.10*** 0.03	− 0.07*** 0.01
Proxy status (reference = no proxy)				
Proxy	− 0.23*** 0.04	− 0.09*** 0.03	− 0.28*** 0.04	− 0.10*** 0.02
Observations	869	869	869	869
Weighted <i>N</i>	129,836	129,836	129,836	129,836
<i>F</i> (26, 46)	26.06	41.68	11.88	47.29
Probability > <i>F</i>	.0000	.0000	.0000	.0000

Note. Balanced Repeated Replicate standard errors are beneath the marginal effects.

Logistic regression coefficients available upon request.

*Significant at $p \leq .1$;

**Significant at $p \leq .05$;

***Significant at $p \leq .01$.

SSI, Supplemental Security Income.

Source. Author's calculations from the National Survey of SSI Children and Families.

(Table 2), adjusting for other characteristics. When health characteristics are included in the models (column 2), the raw differences only slightly change; in fact, they increase by 1–4 percentage points. However, when insurance status is included in the models (column 3), the effect of SSI completely disappears for all but the unmet prescription drug needs model. When all insurance and health variables (column 4) and all other variables (column 5) are included, the effect of SSI is still not statistically significant in the any unmet need and unmet medical need regressions.

There is a statistically significant impact of *negative* 9 percentage points ($p = .00$) for unmet dental needs in the fully adjusted model, suggesting young adults who remain on SSI are more likely to have unmet dental needs than those who leave SSI (panel C, column 5).

Although the inclusion of insurance variables reduces the impact of leaving SSI on the presence of unmet prescription drug needs by more than 20 percentage points, the difference remains significant; those on SSI after the age-18 redetermination are still 9 percentage points ($p = .00$) more likely to report having unmet prescription drug needs in the fully adjusted model (panel D, column 5).

Health and Insurance Status

There are also important findings when considering the magnitude of the impacts of the health and insurance variables in the adjusted model (Table 3, which form the basis of column 5 of Table 2). Lack of insurance has the largest impact on any of the unmet need categories. Relative to youth with Medicaid insurance, the uninsured are 48 percentage points ($p = .00$) more likely to report any unmet need, 42 percentage points ($p = .00$) more likely to report an unmet medical need, 33 percentage points ($p = .00$) more likely to report an unmet dental need, and 27 percentage points ($p = .00$) more likely to report an unmet prescription drug need. The only other insurance variable significant at the 5 percent level is the impact of non-Medicaid insurance on unmet prescription drug needs (7 percentage points, $p = .02$). Non-Medicaid insurance and Medicaid insurance are generally not statistically different from each other, all else equal.

Those in very good or excellent health are less likely than young adults in poor health to report unmet needs and those with more severe disabilities are also generally more likely to report unmet needs in the adjusted model. Not surprisingly, young adults with behavioral and other mental disorders show the highest risk for an unmet prescription drug need, although the difference is not large (4 percentage points over youth with mental retardation, $p = .02$). Additionally, young adults with more severe disabilities and “other” disabilities are more likely to have an unmet dental need than those with mental retardation.

DISCUSSION

While there are large gaps in unmet needs between youth who exit SSI and youth who continue on SSI, the results of this study show that health insurance accounts for most of these gaps; health status has little impact. This is

consistent with the expectation that exiting youth are likely to be healthier, although the subjective nature of the questions means the possibility that these individuals are not aware of their needs because of their lack of insurance cannot be ruled out.

The high prevalence of unmet needs is not atypical for SSI recipients. Long, Coughlin, and Kendall (2002) found that 13 percent of adult SSI recipients in New York City had an unmet need for doctor's care, 15 percent had an unmet dental need, and 11 percent had an unmet prescription drug need. While these estimates are much higher for dental needs in the current sample, the other estimates are not too dissimilar.

Compared with DeCesaro and Hemmeter (2009), who found that 9 percent of children under age 18 on SSI report having an unmet need, I found that 32 percent of those on SSI after the age-18 redetermination and 59 percent of those off SSI after the age-18 redetermination have an unmet need. The increase in the percentage on SSI with an unmet medical need could be due to differences in the Medicaid packages offered to children and adults; however, DeCesaro and Hemmeter ignored children without insurance, which likely biases their results downward.¹²

Youth who exit SSI after the age-18 redetermination fare considerably worse than similarly aged young adults in the general population. Callahan and Cooper (2005) found that 22–26 percent of uninsured young adults age 19–24 delayed or missed medical care due to cost in the past 12 months and 12–18 percent had an unmet prescription drug need due to cost. Lotstein et al. (2008) found that among a small sample young adults ages 21–24, SSI recipients were less likely to experience an “adverse transition event” (including delaying or forgoing care).

Although insurance coverage lowers the prevalence of unmet needs, the results of this study indicate that a large percentage of young adults on and off SSI have unmet health care needs, even youth covered by Medicaid. This suggests some level of underinsurance among these individuals. The difference between the unmet needs of continuing- and exiting-SSI youth is greatest with respect to prescription drug access (a 30 percentage point difference). Those with behavioral and mental impairments other than mental retardation, which can often be moderated by prescription medications, were found to be more likely to have prescription drug needs. These groups are also among the most likely to be ceased as a result of the age-18 redetermination (Rogowski et al. 2002; Hemmeter and Gilby 2009).

It is not clear why so few of those who left SSI in this study have health insurance, particularly Medicaid. This may partly be due to the self-reported

nature of the insurance variable: some may simply not be aware that they are eligible for Medicaid in the absence of SSI. In the survey, only about 36 percent of young adults off SSI were employed, compared with 70 percent of young adults ages 20–24 in the general population (Bureau of Labor Statistics 2010). The low connection to the labor force may preclude some youth from finding employer-provided coverage. The recently enacted health care legislation may provide more health care options for these young adults.

Wang, Grembowski, and Watts (2009) suggested additional Medicaid eligibility pathways may be appropriate for youth with nonsevere disabilities, which could include youth found ineligible for SSI at their age-18 redetermination. This might be a feasible and relatively quick way of helping provide for the needs of young adults who leave SSI, especially as a bridge to whatever plans are available under the new legislation. However, given the high rate of poverty among those off SSI, this may not be a viable option for many young adults. Similarly, recent research by Levine, McKnight, and Heep (2009) has shown that the State Children's Health Insurance Program expands health insurance coverage for this age group. However, this may place an unfunded burden on the states.

Lotstein et al. (2005, 2009) have shown that health-related planning for the transition to adulthood is not common, even though 62 percent of pediatricians treating children over age 13 think this planning should occur at ages 18–20 for adolescents with special health care needs (McManus et al. 2008) and several physician groups argue for earlier planning (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine 2002). This lack of health-related preparation for adulthood potentially leaves many SSI youth unprepared for the potential ineligibility for SSI and/or Medicaid; the disparity in health insurance access as an adult and as a child is very large, especially for former SSI youth (White 2002). The results from the current paper suggest that future efforts might consider structured health-related transition planning for SSI youth.¹³

Limitations

There are several issues that should be noted when interpreting the results. First, as indicated, this study relies on self-reported needs, which can be subjective. However, these questions have been used in several surveys and are the basis for the literature on unmet needs and this should not detract from their usefulness in this study.

Second, the cross-sectional nature of the data excludes a direct association of causality between leaving SSI and the presence of an unmet need.

Although there may be differences in the characteristics of youth before the age-18 redetermination, all youth were on SSI as a child and, as a result, most likely had access to Medicaid services. A longitudinal analysis comparing the unmet needs of youth before and after the age-18 redetermination, while beyond the capabilities of the current dataset, would be preferred. Additionally, while I control for their SSA-determined childhood disability, differences in motivation and ability may remain; however, the results are consistent with a priori expectations about health status, insurance coverage, and SSI participation.

Third, there are likely state- and region-level differences in the availability and costs of receiving care, which are not controlled for in this study. Finally, the unmet need questions used in this study refer to 12 months before the survey, while the insurance variables refer to the month before the survey. As a result, there could be some times in the previous year when an uninsured individual had insurance or vice versa, which would lead to measurement error. However, only 6 percent of the sample experienced a change in insurance status in the past year and the results are consistent with expectations.

The transition to adulthood for youth with disabilities can be very challenging, especially with respect to health care. The findings of this paper suggest the transition can be more difficult for those who leave SSI after the age-18 redetermination, especially youth without health insurance. It will be important to determine in future research whether the recent health care legislation reduces the unmet health needs of this vulnerable group or if there may still be institutional barriers, such as transferring from Medicaid-eligibility through SSI receipt to non-SSI-based Medicaid eligibility, that impede access to care.

NOTES

1. For more information on the age-18 redetermination, see Hemmeter and Gilby (2009); for more information on SSI eligibility rules, see SSA (2008); and for more information on how the age-18 redetermination affects youth, see Johnson et al. (2007).
2. There is a substantial body of literature identifying the adverse effects of the lack of insurance on health and economic outcomes later in life (cf. Levy and Meltzer 2004; Hadley 2002; Levine et al. 2009).
3. Because the age-18 redetermination is mandatory for all youth and is based solely on the health status of the youth, which is measured both by the disability, it is plausible that the SSI status of the sample can be considered exogenous. As a test of whether the timing of the measures of the variables matters (e.g., if health status has changed because the redetermination), regressions were run limiting the sample to youth age 19 (who have recently had their redetermination). The results, available upon

- request, indicate that the effect of SSI receipt would be statistically significant, positive, and larger in magnitude for this subsample for all but unmet medical needs.
4. This file was extracted in January 2007 from SSA's administrative record and includes information on all age-18 redeterminations through 2005.
 5. The final redetermination decision, including appeals, is used as the administrative comparison. Forty youth had been allowed to continue on SSI as a result of the age-18 redetermination but were not receiving SSI at the time of the survey, and 55 had their eligibility ceased as a result of the age-18 redetermination but were receiving SSI at the time of the survey. These youth are not included in the analysis to ensure that the SSI participation variable is the result of the age-18 redetermination. Three hundred and ten youth who did not have an age-18 redetermination are also excluded from the sample. In addition to these deletions based on the redetermination outcomes, nine youth were removed for not having complete income data; all other missing values were included in either the "no" responses or the lowest category (poor health or low severity/no disability). Self-reported SSI status was confirmed in administrative records.
 6. For medical care, the survey instrument was as follows: "In the past 12 months, have you delayed or gone without health care for any reason?" For prescription drugs, it was as follows: "During the past 12 months, was there any time when you needed prescription medicines but didn't get them?" For dental care, it was as follows: during the past 12 months, was there any time when you needed dental care, including check-ups, but didn't get it?"
 7. Very good and excellent are combined due to low cell sizes in some of the analyses. The main results are not changed when they are separated.
 8. Disability severity is measured based on a ranking of how the respondent ranks his or her health problems on a scale of 0 (mildest) to 10 (most severe). A high severity disability is defined as a ranking of 7–10; a moderate severity disability is rankings 4–6; and a low severity disability or no disability is rankings 0–3.
 9. Sensory and systemic disorders include diseases of the nervous system and sensory organs and diseases of the circulatory, digestive, genitourinary, musculoskeletal, and respiratory systems. The behavioral and other mental disorders category includes affective, anxiety, schizophrenia, and other mental disorders. The other disabilities category includes all other diseases and disorders. These disabilities are the primary disability in SSA administrative records; individuals may have other impairments that contribute to the youth's level of need which are not captured by this measure.
 10. Some youth may be covered by Medicaid but not be aware of their coverage. I treat these youth as uninsured because their receipt of medical care and subjective answers to survey questions reflect their belief of being uninsured.
 11. Proxy status may also be considered a bridge between the need for care and ability to receive care variables. For instance, an individual who required a proxy arguably has a greater need for care and may also have a greater ability to receive care (or at least a support system for receiving care). Because it does not fit well into the Aday–Andersen framework, it was kept separate from these variable domains. Note that the main variables of interest (SSI status and redetermination outcome) are either not self-reported or were verified in administrative records. In

regressions available upon request, there is clearly a relationship between disability type, severity of disability, and proxy status. Multicollinearity may confound the interpretation of the estimated coefficients on these variables.

12. This restriction only reduced their sample by 1 percent, much less than the gap measured in this study.
13. SSA is currently testing similar employment and self-sufficiency supports for this population in the Youth Transition Demonstration project (Fraker and Rangarajan 2009).

REFERENCES

- Aday, L. A., and R. Andersen. 1974. "A Framework for the Study of Access to Medical Care." *Health Services Research* 194: 208–20.
- American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine. "A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs." *Pediatrics* 110 (6): 1304–6.
- Bartus, T. 2005. "Estimation of Marginal Effects Using Margeff." *Stata Journal* 5 (3): 309–2.
- Bureau of Labor Statistics. 2010. "(Unadj) Employment–Population Ratio—20–24 yrs. Series LNU02300036Q" [accessed August 16, 2010]. Available at <http://data.bls.gov/cgi-bin/srgate>
- Burstin, H. R., K. Swartz, A. C. O'Neil, E. John Orav, and T. A. Brennan. 1998/1999. "The Effect of Change of Health Insurance on Access to Care." *Inquiry* 35: 389–97.
- Callahan, S. T., and W. O. Cooper. 2005. "Uninsurance and Health Care Access among Young Adults in the United States." *Pediatrics* 116 (1): 88–95.
- . 2006. "Access to Health Care for Young Adults with Disabling Chronic Conditions." *Archives of Pediatric and Adolescent Medicine* 160 (2): 178–82.
- . 2007. "Continuity of Health Insurance Coverage among Young Adults with Disabilities." *Pediatrics* 119 (6): 1175–80.
- Cummings, J. R., S. A. Lavarreda, T. Rice, and E. Richard Brown. 2009. "The Effects of Varying Periods of Uninsurance on Children's Access to Health Care." *Pediatrics* 123 (3): e411–8.
- Davies, P. S., and K. Rupp. 2005/2006. "An Overview of the National Survey of SSI Children and Families and Related Products." *Social Security Bulletin* 66 (2): 7–20.
- DeCesaro, A., and J. Hemmeter. 2009. "Unmet Health Care Needs and Medical Out-of-Pocket Expenses of SSI Children." *Journal of Vocational Rehabilitation* 30 (3): 177–99.
- Fishman, E. 2001. "Aging Out of Coverage: Young Adults with Special Health Needs." *Health Affairs* 20 (6): 254–66.
- Fraker, T., and A. Rangarajan. 2009. "The Evaluation of SSA's Youth Transition Demonstration Projects." *Journal of Vocational Rehabilitation* 30 (3): 223–40.

- Gillcrest, J., and D. Edson. 2004. *National Survey of SSI Children and Families User's Manual for Restricted and Public Use Files*. Mathematica Policy Research Inc, MPR Reference No.: 8761-940.
- Hadley, J. 2002. *Sicker and Poorer: The Consequences of Being Uninsured*. Kaiser Commission on Medicaid and the Uninsured, May.
- Hemmeter, J., and E. Gilby. 2009. "The Age-18 Redetermination and Postredetermination Participation in SSI." *Social Security Bulletin* 69 (4): 1-25.
- Hemmeter, J., J. Kauff, and D. Wittenburg. 2009. "Changing Circumstances: Experiences of Child SSI Recipients before and after Their Age-18 Redetermination for Adult Benefits." *Journal of Vocational Rehabilitation* 30: 201-2.
- Johnson, D. R., M. McEathron, J. Fields, and K. Hill. 2007. *A Qualitative Study of the Experiences of Transition-Age Youth with Disabilities in Relation to SSI Redetermination*. Policy Research Brief: University of Minnesota. Available at <http://ici.umn.edu/products/prb/181/default.html>
- Levine, P. B., R. McKnight, and S. Heep. 2009. *Public Policy, Health Insurance and the Transition to Adulthood*. NBER Working Paper No. 15114, June.
- Levy, H., and D. Meltzer. 2004. "What do We Really Know about Whether Health Insurance Affects Health?" In *Health Policy and the Uninsured*, edited by G. M. Catherine, pp. 179-204. Washington, DC: Urban Institute Press.
- Long, S. K., T. A. Coughlin, and S. J. Kendall. 2002. "Access to Care among Disabled Adults on Medicaid." *Health Care Financing Review* 23 (4): 159-73.
- Loprest, P., and D. Wittenburg. 2007. "Posttransition Experiences of Former Child SSI Recipients." *Social Service Review* 81 (4): 583-608.
- Lotstein, D. S., R. Ghandour, A. Cash, E. McGuire, B. Strickland, and P. Newacheck. 2009. "Planning for Health Care Transitions: Results from the 2005-2006 National Survey of Children with Special Health Care Needs." *Pediatrics* 123 (1): e145-52.
- Lotstein, D. S., M. Inkelas, R. D. Hays, N. Halfon, and R. Brook. 2008. *Journal of Adolescent Health* 43: 23-9.
- Lotstein, D. S., M. McPherson, B. Strickland, and P. W. Newacheck. 2005. "Transition Planning for Youth with Special Health Care Needs: Results from the National Survey of Children with Special Health Care Needs." *Pediatrics* 115 (6): 1565-8.
- McManus, M., H. Fox, K. O'Connor, T. Chapman, and J. MacKinnon. 2008. *Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care*. National Alliance to Advance Adolescent Health Fact Sheet-No 6, October.
- Newacheck, P. W., D. C. Hughes, Y.-Y. Hung, S. Wong, and J. J. Stoddard. 2000. "The Unmet Health Needs of America's Children." *Pediatrics* 105 (4): 989-97.
- Olson, L. M., S.-F. S. Tang, and P. W. Newacheck. 2005. "Children in the United States with Discontinuous Health Insurance Coverage." *New England Journal of Medicine* 353 (4): 382-91.
- Rogowski, J., L. Karoly, J. Klerman, M. Inkelas, M. Rowe, and R. Hirscher. 2002. *Final Report for Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children, DRU-2559-SSA*. Santa Monica, CA: The RAND Corporation.

- Scal, Peter, and Marjorie Ireland. 2005. "Addressing Transition to Adult Health Care for Adolescents with Special Health Care Needs." *Pediatrics* 115 (6): 1607–12.
- Sintonen, H., and I. Linnosmaa. 2000. "Economics of Dental Services." In *Handbook of Health Economics*, Vol. 1B, edited by J. C. Anthony and J. P. Newhouse, pp. 1251–96. Amsterdam: Elsevier.
- Social Security Administration (SSA). 2008. SSI Annual Statistical Report, Office of Research, Evaluation, and Statistics, September.
- Social Security Administration (SSA). 2009. Annual Report of the Supplemental Security Income Program, Office of the Chief Actuary, May.
- Wang, G., D. Grembowski, and C. Watts. 2009. "Health Insurance Regain after a Spell of Uninsurance: A Longitudinal Comparison of Youth with and without Disabilities Transitioning into Adulthood." *Journal of Adolescent Health* 45: 556–63.
- White, P. H. "Access to Health Care: Health Insurance Considerations for Youth Adults with Special Health Care Needs/Disabilities." *Pediatrics* 110 (6): 1328–35.
- Williams, B., and J. Tolbert. 2007. *Aging out of EPSDT: Issues for Young Adults with Disabilities*. Kaiser Commission on Medicaid and the Uninsured Issue Paper.