

Income Growth Trajectory for Parents of Children with Down Syndrome in the United States

David Samuelson, BA¹; Andrew Kageleiry, BS¹; Mei Sheng Duh, ScD, MPH¹; Patrick Lefebvre, MA¹; John Campbell, PhD²; Maral DerSarkissian, PhD¹; Batool Haider, MD, MS, ScD¹; Brian G. Skotko, MD, MPP^{3,4}

¹ Analysis Group, Inc., Boston, MA, USA; ² Department of Economics, Harvard University, Cambridge, MA, USA; ³ Division of Medical Genetics, Department of Pediatrics, Massachusetts General Hospital, Boston, MA, USA; ⁴ Harvard Medical School, Boston, MA, USA

Background

- The new non-invasive prenatal screening (NIPS) test, available as of October 2011, allows couples to learn whether their fetus has Down syndrome (DS) as early as 9 weeks into gestation
- Given the availability of this test, more couples are expected to receive a prenatal diagnosis of DS¹⁻⁴
- Upon receiving a prenatal DS diagnosis, expectant parents must make decisions about their pregnancy options with limited time and information⁵
- Some couples may be concerned about the financial impact of raising a child with DS
 - Costs include both direct costs, such as paying for care, and indirect costs, such as the potential impact of having to care for the child, on career progression and income
- Previous research has examined the impact of having a child on parents’ earnings⁶⁻⁸
- To our knowledge, no research has examined the differential impact on income growth trajectory of parents of children with DS as compared to parents of children without any chromosomal conditions

Study Objective

To determine whether the rate of income growth among parents of children with DS differs from that among parents of children without chromosomal conditions

Methods

Data

- Data from the OptumHealth Reporting and Insights employer-based claims database were used to conduct this retrospective cohort study
 - The database contains administrative claims (medical and pharmacy claims) and eligibility information for over 18 million individuals who are privately insured through their employers, including primary subscribers and their covered beneficiaries
 - The database covers the period from the first quarter of 1999 through the first quarter of 2015 and has been cited in many peer-reviewed publications⁹⁻¹¹

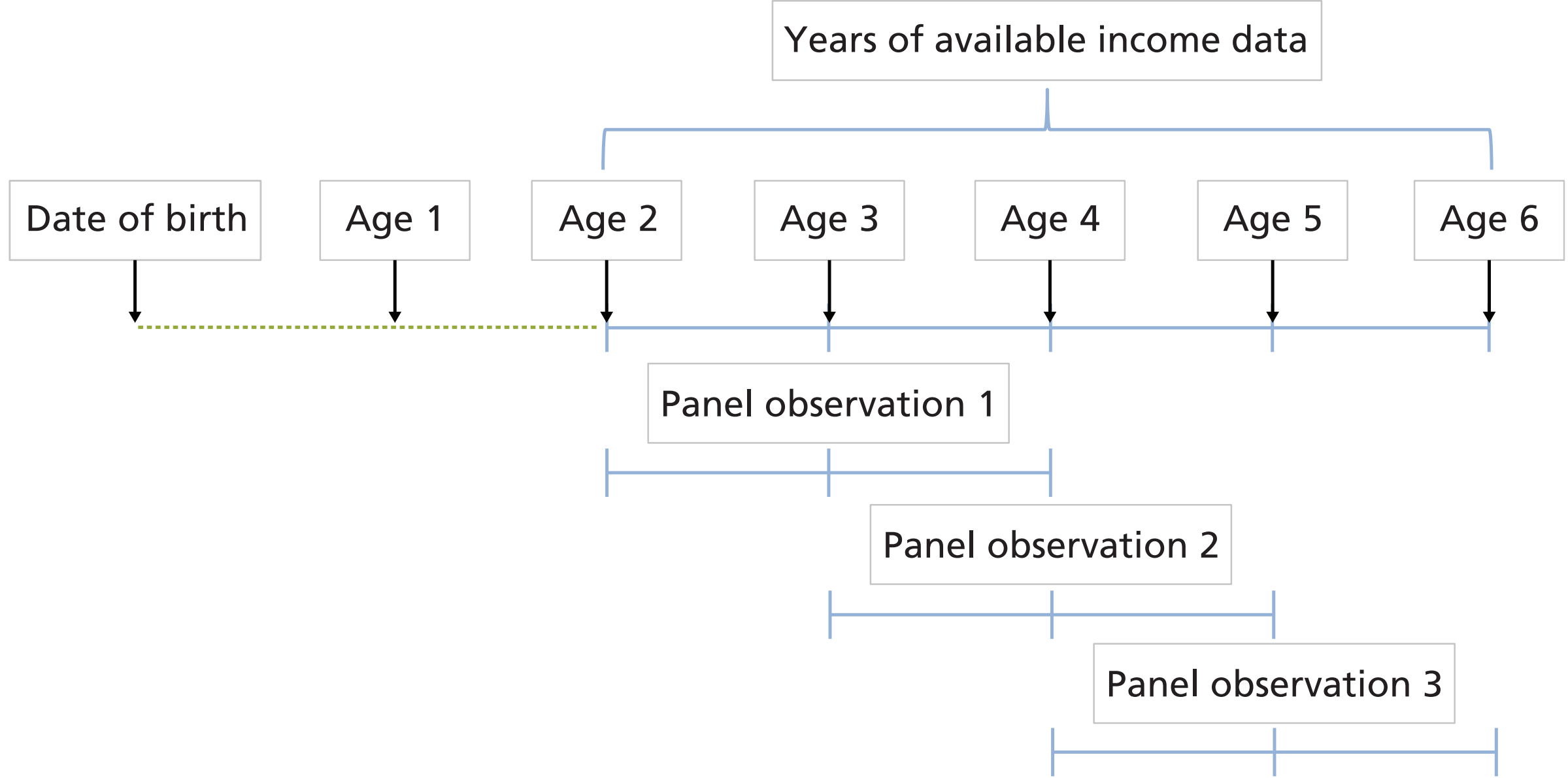
Selection Criteria

- Parents were selected to be included in the study if they were enrolled in their family insurance plan as a plan subscriber; had an identifiable child (<18 years of age) on their insurance plan; had ≥2 consecutive years of income information; and had discernable demographic and enrollment characteristics to use in the matching algorithm
 - DS study group: parents of a child with at least one medical claim associated with a diagnosis of DS (ICD-9-CM code: 758.0x)
- Control group: parents of one or more children, all without any diagnoses of chromosomal conditions (ICD-9-CM code: 758.xx)

Observation Time

- A panel of pairs of consecutive years of parents’ income information was created. Parents with more than two consecutive years of income data were included multiple times (**Figure 1**)
- Parents in the control group with multiple children were included multiple times within the panel for each child

Figure 1. Study Scheme



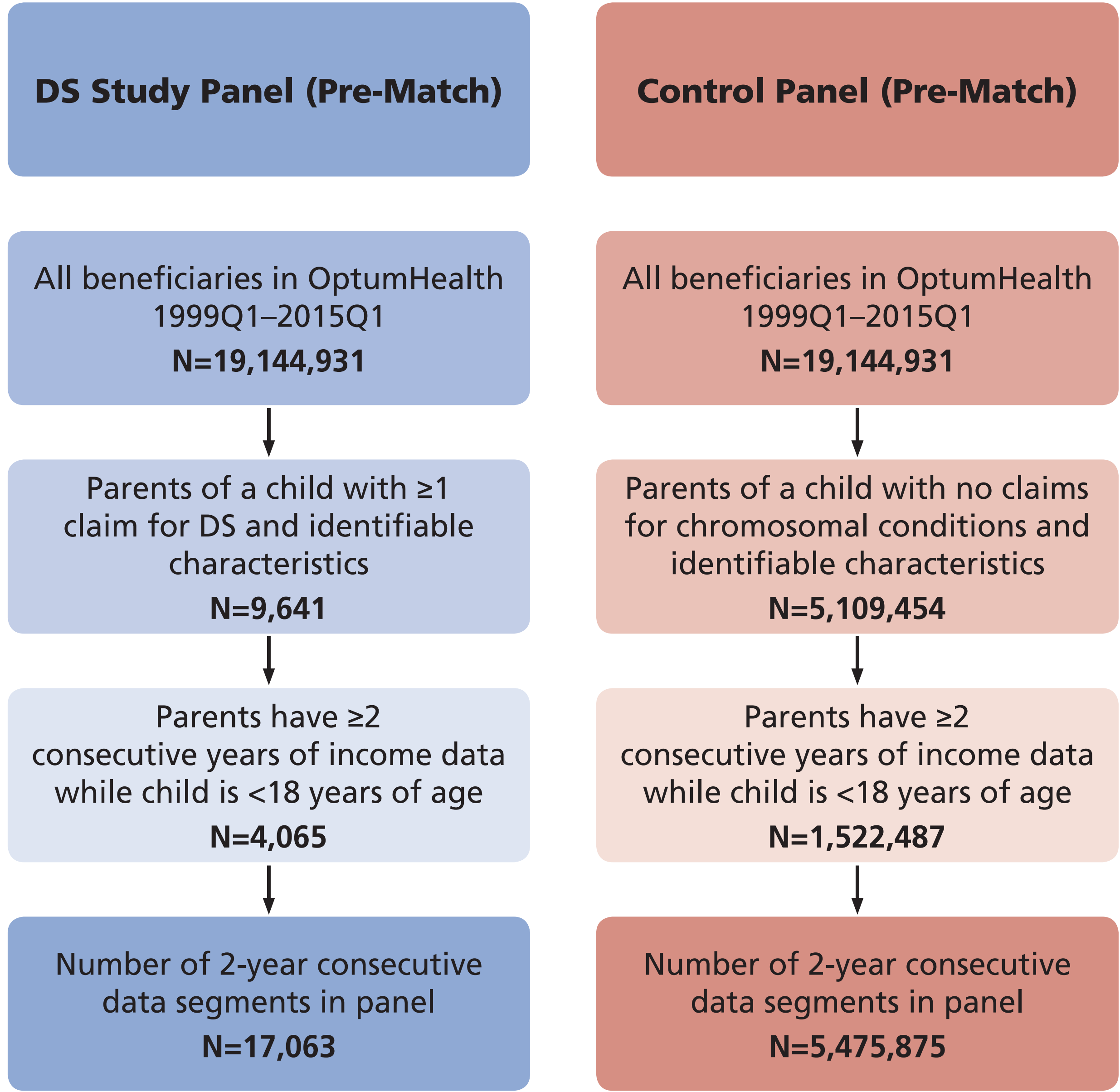
Patient Matching

- Parents within the DS study panel were matched to parents within the control panel in a 1:1 ratio using a greedy matching algorithm^{12,13}
 - Exact matching was used to match parent observations on gender, parental age at child's birth, child's age at the beginning of the two year income observation period, and parental work industry
- A propensity score was calculated for each parent observation using logistic regression to estimate the probability of belonging to the DS study panel; the propensity score model included terms for the parents’ census region and health insurance plan type
- Parent observations in the DS study panel and control panel were matched to within a quarter of a standard deviation of the propensity score

Baseline Characteristics, Outcomes, and Statistical Analysis

- Baseline characteristics
 - Parent characteristics: age, sex, region, insurance plan type, work industry
 - Child's age at time of study
- Study outcomes
 - Mean annual income growth between consecutive years with at least 6 months of populated income information
 - Annual incomes adjusted to 2015 USD using the Consumer Price Index
- Analyses
 - Mean log annual income growth was compared between the two panels using Wilcoxon signed-rank tests

Figure 2: Sample Selection



Results

Baseline Characteristics of Study Participants: Pre- vs. Post-Matching

• After matching, parents of children with DS were similar to their matched controls on baseline characteristics (N=17,062 per matched panel) (**Table 1**)

Table 1. Baseline Characteristics of Parents in DS Study and Control Panels

	DS study panel N=17,063	Pre-Match Control panel N=5,475,875	P-Value ¹	Post-Match DS study panel N=17,062	Control panel N=17,062	P-Value ¹
Descriptive characteristics						
Female, N (%)	8,371 (49.1)	2,698,059 (49.3)	0.580	8,371 (49.1)	8,371 (49.1)	1.000
Age at child's birth (years), mean (SD)	34.3 (6.3)	29.3 (6.4)	<.001 *	34.3 (6.3)	34.3 (6.3)	1.000
Region, N (%)						
Midwest	4,615 (27.0)	1,273,517 (23.3)	<.001 *	4,614 (27.0)	4,614 (27.0)	1.000
Northeast	2,619 (15.3)	880,675 (16.1)	0.009 *	2,619 (15.3)	2,615 (15.3)	0.952
South	6,403 (37.5)	2,032,009 (37.1)	0.260	6,403 (37.5)	6,399 (37.5)	0.964
West	3,249 (19.0)	1,182,957 (21.6)	<.001 *	3,249 (19.0)	3,257 (19.1)	0.912
Insurance Plan Type, N (%)						
HMO	1,812 (10.6)	782,635 (14.3)	<.001 *	1,812 (10.6)	1,808 (10.6)	0.944
Indemnity	1,082 (6.3)	329,050 (6.0)	0.068	1,082 (6.3)	1,070 (6.3)	0.789
POS	3,683 (21.6)	1,049,814 (19.2)	<.001 *	3,683 (21.6)	3,679 (21.6)	0.958
PPO	9,751 (57.1)	2,946,801 (53.8)	<.001 *	9,750 (57.1)	9,779 (57.3)	0.751
Other	735 (4.3)	367,575 (6.7)	<.001 *	735 (4.3)	726 (4.3)	0.810
Work industry, N (%)						
Financial Services	930 (5.5)	410,549 (7.5)	<.001 *	929 (5.4)	929 (5.4)	1.000
Healthcare	1,241 (7.3)	470,972 (8.6)	<.001 *	1,241 (7.3)	1,241 (7.3)	1.000
Manufacturing/Energy	2,807 (16.5)	816,354 (14.9)	<.001 *	2,807 (16.5)	2,807 (16.5)	1.000
Retail/Consumer Goods	918 (5.4)	427,007 (7.8)	<.001 *	918 (5.4)	918 (5.4)	1.000
Shipping/Transportation	5,234 (30.7)	1,503,797 (27.5)	<.001 *	5,234 (30.7)	5,234 (30.7)	1.000
Technology	4,698 (27.5)	1,503,807 (27.5)	0.836	4,698 (27.5)	4,698 (27.5)	1.000
Other	1,235 (7.2)	343,389 (6.3)	<.001 *	1,235 (7.2)	1,235 (7.2)	1.000
Child's age at time of study, N (%)						
< 3 years	2,184 (12.8)	492,475 (9.0)	<.001 *	2,184 (12.8)	2,184 (12.8)	1.000
3–5 years	3,324 (19.5)	820,454 (15.0)	<.001 *	3,323 (19.5)	3,323 (19.5)	1.000
6–9 years	4,292 (25.2)	1,209,769 (22.1)	<.001 *	4,292 (25.2)	4,292 (25.2)	1.000
10–15 years	5,676 (33.3)	2,125,185 (38.8)	<.001 *	5,676 (33.3)	5,676 (33.3)	1.000
> 15 years	0 (0.0)	0 (0.0)	--	0 (0.0)	0 (0.0)	--

Notes
* P-value <0.05.
[1] P-values before matching were calculated using Wilcoxon rank-sum tests for continuous variables and chi-square tests for categorical variables. P-values after matching were calculated using McNemar tests and Wilcoxon signed-rank tests.

Income Growth

- Parents of children with DS have lower mean annual income growth rate than their matched controls (4.0% vs. 4.1%, p=0.027). Though statistically significant, the magnitude of difference was small (**Table 2**)
- No statistically significant differences existed in mean annual income growth rate when analyzed separately for mothers (4.0% vs. 4.2%, p=0.193) and fathers (3.9% vs. 4.0%, p=0.070) (**Table 2**)

Table 2: Mean Annual Growth Rate in Incomes Amongst parents of Children with DS and Matched Controls

	DS study panel	Control panel	Difference	P-Value ¹
Overall	N=17,062	N=17,062		
Mean log difference in annual income, mean ± SD	0.039 ± 0.082	0.040 ± 0.101	-0.001	0.027*
Average change in annual income (%) ²	4.0%	4.1%	-0.10%	
Mothers	N=8,371	N=8,371		
Mean log difference in annual income, mean ± SD	0.040 ± 0.084	0.041 ± 0.107	-0.001	0.193
Average change in annual income (%) ²	4.0%	4.2%	-0.13%	
Fathers	N=8,691	N=8,691		
Mean log difference in annual income, mean ± SD	0.039 ± 0.080	0.039 ± 0.095	-0.001	0.070
Average change in annual income (%) ²	3.9%	4.0%	-0.07%	

Notes
* P-value <0.05.
[1] P-values were calculated using Wilcoxon signed-rank tests.
[2] Percentages calculated from log differences using the following equation: average change=e^{mean log difference} – 1.

Discussion

- Parents of children with DS have lower mean annual income growth compared to those of children without chromosomal conditions. This difference was not statistically significant among mothers and fathers when analyzed separately
- Using the 2014 US median income of \$50,383 and \$39,621 among yearly full-time working men and women, respectively, this difference in income growth translates into \$35 annual reductions for fathers and \$52 annual reductions for mothers
- Previous studies have shown that having a child affects mothers’ salaries differently than fathers’. Our study did not test for an interaction between having a child with DS and parents’ gender, but further research is warranted
- Further research is merited to determine whether the impact of having a child with DS on parents’ income differs with the age of the child

Limitations

- As claims data were used for the study, any missing information or administrative error may have resulted in confounding, selection bias, and/or measurement error
- Administrative claims databases are used for the reimbursement of healthcare services and thus do not contain detailed information on other clinical disease characteristics that may affect parents’ income trajectory. Failure to adjust for these characteristics in the analysis may bias the results
- The current study focuses on income data for plan subscribers, and the findings may not be generalizable to the income growth trajectory of spouses or secondary earners
- Parents of children with DS who may not have received a DS diagnosis code on an insurance claim and thus are not included in the DS study group likely represent parents of relatively healthier children with DS, as doctors did not consider DS a co-occurring condition. These patients’ less severe health issues may have a smaller impact on their parents’ income growth trajectory. Though it is unlikely, inclusion of these parents in the study as controls would have minimized the differences in mean annual income between the two groups
- The current study is based on a commercial employer database, and families covered by Medicaid or Medicare are not represented in the database used
- Propensity scores were not calculated separately for mothers and fathers, and thus residual confounding may remain in the gender-specific cohorts

Conclusions

- Parents of children with DS experience lower mean annual income growth than parents of children without chromosomal conditions
- Based on the 2014 US median income, this difference translates into \$35 reductions in annual income growth for fathers and \$52 reductions for mothers
- The potential impact on income growth is a part of the financial consideration for parents receiving a prenatal DS diagnosis; further research is needed to consider potential costs associated with caring for children with DS
- The current study evaluated only the impact of having a child with DS on the plan subscriber's income growth. The findings cannot be generalized to secondary earners, among whom the impact may be different

References

- Skotko BG. 2005. Prenatally diagnosed down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *Am J Obstet Gynecol* 192: 670–677.
- Bianchi DW, Platt LD, Goldberg JD, Abuhamad AZ, Sehnert AJ, Rava RP, Maternal Blood IS Source to Accurately diagnose fetal aneuploidy (MELISSA) DS case group. 2012. Genome-wide fetal aneuploidy detection by maternal plasma DNA sequencing. *Obstet Gynecol* 119: 890–901.
- Nicolaides KH, Syngelaki A, Ashoor G, Birdir C, Touzet G. 2012. Noninvasive prenatal testing for fetal trisomies in a routinely screened first-trimester population. *Am J Obstet Gynecol* 207: 374.e1–374.e6.
- Norton ME, Brar H, Weiss J, Karimi A, Laurent LC, Caughey AB, Rodriguez MH, Williams J,3rd, Mitchell ME, Adair CD, Lee H, Jacobsson B, Tomlinson MW, Oepkes D, Holleman D, Sparks AB, Oliphant A, Song K. 2012. Non-invasive chromosomal evaluation (NICE) study: Results of a multicenter prospective cohort study for detection of fetal trisomy 21 and trisomy 18. *Am J Obstet Gynecol* 207: 137.e1–137.e8.
- Zimmermann B, Hill M, Gemelos G, Demko Z, Banjevic M, Baner J, Ryan A, Sigurjonsson S, Chopra N, Dodd M, Levy B, Rabinowitz M. 2012. Noninvasive prenatal aneuploidy testing of chromosomes 13, 18, 21, X, and Y, using targeted sequencing of polymorphic loci. *Prenat Diagn* 32: 1233–1241.
- Budig M, England P. 2001. The wage penalty for motherhood. *American Sociological Review*. 66: 204–225.
- Waldfogel J. 1997. The effect of children on women's wages. *American Sociological Review*. 62: 209–217.
- Glauber R. 2007. Marriage and the Motherhood Wage Penalty Among African Americans, Hispanics, and Whites. *Journal of Marriage and the Family*. 69: 951–961.
- Rice JB, Kirson NY, Shei A, Cummings AK, Bodnar K, Birnbaum HG, Ben-Joseph R. 2014. Estimating the costs of opioid abuse and dependence from an employer perspective: A retrospective analysis using administrative claims data. *Appl Health Econ Health Policy* 12: 435–446.
- Loftus EV,Jr, Skup M, Ozbay AB, Wu E, Guerin A, Chao J, Mulani P. 2014. The impact of moderate-to-severe Crohn's disease on employees' salary growth. *Inflamm Bowel Dis* 20: 1734–1738.
- Rice JB, Desai U, Cummings AK, Birnbaum HG, Skornicki M, Parsons NB. 2014. Burden of diabetic foot ulcers for medicare and private insurers. *Diabetes Care* 37: 651–658.
- Miettinen OS. 1969. Individual matching with multiple controls in the case of all-or-none responses. *Biometrics* 25: 339–355.
- Bergstralh EJ, Kosanke JL. 1995. Computerized matching of controls. Technical Report Series No. 56, Department of Health Science Research, Mayo Clinic, Rochester.