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Author manuscript Acad Pediatr. Author manuscript; available in PMC 2014 May 01.

Published in final edited form as: *Acad Pediatr.* 2013 ; 13(3): 222–228. doi:10.1016/j.acap.2013.01.001.

# Double Bind: Primary Caregivers of Children with Special Health Care Needs and Their Access to Leave Benefits

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# Abstract

**Objective**—Family leave benefits are a critical tool allowing parents to miss work to care for their ill children. We examined whether access to benefits varies by level of childcare responsibilities among employed parents of children with special health care needs (CSHCN).

**Methods**—We conducted telephone interviews with three successive cohorts of employed parents of CSHCN, randomly sampled from a California children's hospital. At Wave 1 (November 2003 to January 2004) we conducted 372 parent interviews. At Wave 2 (November 2005 to January 2006) we conducted 396 parent interviews. At Wave 3 (November 2007 to December 2008) we conducted 393 parent interviews. We pooled these samples for bivariate and multivariate regression analyses, using wave indicators and sample weights.

**Results**—Parents with more childcare responsibilities (primary caregivers) reported less access to sick leave/vacation (65% vs. 82%, P < .001), access to paid leave outside of sick leave/vacation (41% vs. 51%, P < .05), and FMLA eligibility (2890025; vs. 44%, P < .001) than secondary caregivers. Part-time employment and female gender largely explained two of the three associations between more childcare responsibilities and less access to leave benefits. Even in the context of part-time employment, however, primary caregivers were just as likely as secondary caregivers both to miss work due to their child's illness and to report being unable to miss work when they needed to.

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CONFLICTS OF INTEREST: The authors have no potential conflicts of interest or corporate sponsors to report.

**Conclusions**—Due in part to employment and gender differences, leave benefits among parents of CSHCN are skewed away from primary caregivers and toward secondary caregivers. Thus, primary caregivers may face particularly difficult choices between employment and childcare responsibilities. Reducing this disparity in access to benefits may improve health for CSHCN and their families.

#### Keywords

chronic disease; family leave; caregivers

# INTRODUCTION

Socio-demographic and economic shifts among American families over the past few decades have resulted in more women entering the workplace and more men contributing to home and childcare tasks.<sup>1, 2</sup> Balancing work and family responsibilities is now a common issue for parents, with 62% of married couples with children relying on two or more sources of income.<sup>3</sup> In families with children with special healthcare needs (CSHCN), this balance is even more tenuous. CSHCN have far more medical encounters, hospitalizations, hospital days, and school absences than other children.<sup>4</sup> During medical encounters and hospitalizations, parents often need to help or comfort their children and engage with health care providers,<sup>5</sup> and during illness-related absences from school or childcare, children require care or supervision.<sup>6</sup> Therefore, employed parents of CSHCN may have a much greater need for time off than other parents.<sup>7, 8</sup>

Family leave policies are designed to help working parents care for ill family members. The federal 1993 Family and Medical Leave Act (FMLA) guarantees up to 12 weeks of unpaid family leave to eligible employees.<sup>9</sup> The FMLA, however, has had only a modest impact on actual leave-taking.<sup>10</sup> This is due not only to eligibility restrictions (only 47% of US employees are eligible<sup>10</sup>) but also to a lack of uptake. Many who are eligible cannot afford to take unpaid leave or fear that they will suffer negative consequences at work if they take leave.<sup>9</sup> Consequently, several states have begun to offer family leave programs.<sup>11–14</sup> California's Paid Family Leave Insurance (PFLI) program, the first statewide paid family leave program in the country, was implemented in 2004 and guarantees up to 6 weeks of partially paid leave to nearly all employees.<sup>11</sup> Our prior research, however, has shown that, among parents of CSHCN, awareness and uptake of the program have been minimal.<sup>15</sup> Therefore, in order to care for ill family members, most employees continue to rely on a patchwork system of formal and informal employer-provided leave.

It is unclear, however, how access to various types of leave is distributed among employed parents of CSHCN. In an efficient system, primary caregivers (those who provide all or most of the childcare) would have equal or greater access to family leave benefits than coprimary caregivers (those who provide about half) or secondary caregivers (those who provide only some or none). This might occur, for instance, if primary caregivers self-select into jobs that provide more generous leave benefits. However, it is also possible that leave benefits are distributed inefficiently, with primary caregivers often having jobs that offer fewer benefits than jobs held by those who have fewer childcare responsibilities. This might

occur, for instance, if primary caregivers—limited by conflicts between work and family responsibilities or by differences in education or career interests—enter lower-benefit sectors or roles or take part-time jobs. Such a pattern would suggest even less useful access to leave benefits than is reported in our previous studies,<sup>15–17</sup> and therefore even less ability for parents of CSHCN to care for their ill children without risking their jobs or income. In this study we explored whether access to sick leave/vacation, other employer-provided paid leave, or FMLA benefits varied by caregiver status among employed parents of CSHCN.

#### METHODS

#### Sampling Frame

We sampled children receiving any care (inpatient or outpatient) at Mattel Children's Hospital at the University of California, Los Angeles (UCLA). Children's hospitals like Mattel provide the vast majority of highly specialized care for children with complex and rare conditions.<sup>18</sup>

We identified CSHCN by adapting a validated ICD-9 billing code approach.<sup>16, 19–27</sup> The unmodified approach generally yields samples dominated by common diagnoses that typically require relatively few missed work days (e.g., asthma, attention deficit/ hyperactivity disorder) than other chronic conditions. Because we were most interested in CSHCN whose parents needed to miss work, we restricted the code-list to disease categories<sup>27</sup> with the highest average per-patient physician charges. These categories included bronchopulmonary dysplasia, cerebral palsy, chronic anemias, chronic enteritis/ colitis, chronic renal failure, congenital heart diseases, cystic fibrosis, degenerative neurologic disorders, hydrocephalus, immunologic disorders, malignancies, organ transplant complications, and rheumatologic disorders. Physician charges have been shown to correlate well with illness severity.<sup>24–27</sup>

Using this list, we recruited three successive cohorts of children by identifying all children (<18 years old) in the hospital's billing database who were assigned a qualifying diagnosis between 10/1/02-9/30/03, 10/1/04-9/30/05, or 10/1/06-9/30/07; listed as alive; and living in California.

Because PFLI is available only to employed people, we focused on CSHCN with employed parents. In order to under-sample parents who were less likely to be employed, we stratified by Medicaid status; details appear elsewhere.<sup>16</sup>

We identified CSHCN at UCLA: 1,570 Wave 1, 1,499 Wave 2, 2,582 Wave 3. At each wave, we randomly selected separate cohorts of 800 children.

#### Data Collection

Telephone interviewers conducted 40-minute computer-assisted-telephone-interviews (English/Spanish) with one parent per child. Details of our process for selecting parents in two-parent households appear elsewhere.<sup>16</sup>

At Wave 1 (11/03-1/04), we interviewed 562 UCLA parents. Excluding parents who were never located (11%) or were otherwise ineligible (2% had moved out-of-state, or their child had died), the response rate was 82%.<sup>28</sup> At Wave 2 (11/05-1/06), 583 UCLA parents participated. Excluding parents who were never located (5.5%) or were otherwise ineligible (4.5%, including those who had moved out-of-state or stopped caring for their child, whose child had died or been misidentified as CSHCN, or who had been in a previous cohort), the response rate was 81%. At Wave 3 (11/07-1/08), we interviewed 587 parents. Excluding parents who were never located (6.6%) or were otherwise ineligible, the response rate was 82%. The pooled response rate across all three waves was 81%.

The UCLA IRB approved the study and provided a HIPAA waiver.

#### Survey

Outcomes and predictors are displayed in Table 1.

**Outcomes**—Respondent employment was assessed with the question, "Are you currently working for pay full-time or part-time? By full-time we mean 30 or more hours per week," with the response options "full-time," "part-time," and "not working." We asked all employed parents whether they had access to employer-provided sick leave or vacation (1=yes, 0=no), and whether they had access to employer-provided paid leave other than sick leave or vacation. We also asked a series of questions to determine whether parents were likely eligible for FMLA leave. To be considered eligible, parents had to have worked 12 months for the same employer and 1,250 hours in the past year for that employer, and the employer needed to have 50 employees. Only parents who met all three requirements were considered eligible for FMLA leave. Finally, we asked parents in Wave 2 and Wave 3 whether they had heard of PFLI; PFLI did not begin until after Wave 1.

**Predictors**—Our main predictor was caregiver status. We asked parents how much of their child's daily care they provided (*all, most, about half, some*, or *none*). Answer categories were collapsed to define three types of caregivers – primary (providing all or most of the care), co-primary (providing about half), and secondary (providing some or none). Sensitivity analyses using other categorizations showed similar results. To account for key potential parent and family-related confounders, we also included information about gender of the responding parent and family structure, including marital status, spouse/partner employment status, and other adults or children in the household.

We also included standard demographic and employment data that might be associated with both caregiver status and access to leave. Many of the employment-related items came from the Department of Labor Survey of Employees. Other items were developed by the researchers; reviewed by clinicians, attorneys, and social scientists familiar with CSHCN and labor issues; and piloted among parents of CSHCN. We included overtime eligibility because having a non-salaried position that is eligible for overtime often indicates both lower job status and a less flexible work schedule. Similarly, we included supervisor status because being a supervisor sometimes indicates both higher job status and greater work schedule flexibility. Supervision was assessed with the question "Do you supervise two or more people?" (yes or no).

We included three child health measures—a PedsQL short version,<sup>29</sup> number of hospitalizations in the past year, and number of hospital nights in the past year—to account for potential associations between serious child health concerns and access to leave benefits. The PedsQL, a standard measure of pediatric health-related quality of life, is not intended for children <2; rather than empirically imputing a score, we assigned these children the mean PedsQL score in our data and marked them with an indicator variable. This approach allowed them to be included in analyses without biasing estimates of PedsQL-related associations. PedsQL scores for healthy children are typically above 80 (out of 100).<sup>33</sup>

**Statistical Analysis**—Analyses incorporated weights accounting for non-response (by applying inverse predicted probabilities of non-response derived from multivariate logistic regressions) and Medicaid-status stratification. No variable was missing >4% at any wave. To prevent bias caused by limiting multivariate analyses to complete cases,<sup>30</sup> we imputed missing observations for key variables using a single chained-equations approach.<sup>31</sup>

The analysis sample for both waves consisted of all part-time and full-time employed parents (372 in Wave 1; 396 in Wave 2; 393 in Wave 3). Because wave did not interact significantly with caregiver status in our main analyses, responses from all three waves were pooled for analyses, with wave indicators included as potential covariates.

For our main analyses, we used access to sick leave or vacation, access to paid leave other than sick leave or vacation, and eligibility for FMLA leave as outcome variables in three sets of bivariate logistic regressions, with all other Table 1 variables as predictors. We then conducted three multivariate logistic regressions to determine whether caregiver status was associated with access to each of the three leave benefits, using Table 1 variables as covariates. To achieve parsimonious and parallel parameterizations across the multivariate models, we set a commonly-used family-wise error rate of  $P < .20^{32}$  in the bivariate regressions as the threshold for admission of a predictor variable into all three multivariate models. This approach resulted in one predictor variable (child gender) being dropped.

We conducted a number of secondary analyses. First, we examined whether caregiver status was associated with awareness of PFLI among parents at Waves 2 and 3. Since the benefit was nearly universally available, awareness was a better measure of access than mere eligibility. Second, we examined whether caregiver status was associated with previously reported measures of parents' need for and use of leave – whether they missed any work in the past year to care for their ill child (1=yes, 0=no), missed >4 weeks of work in the past year to care for their ill child, and were always able to miss work when needing to care for their ill child. Third, it was possible that associations might mask fundamental differences between part-time and full-time employed parents. Therefore, we examined whether the main associations varied by employment status (part-time vs. full-time) by not only interacting employment status with caregiver status, but also repeating the multivariate regressions in sub-analyses of full-time employed parents only. Power was insufficient for sub-analyses of part-time employed parents only.

Analyses were performed using Stata 10 (StataCorp, College Station, Texas). Reported P-values are 2-tailed. Significance level was set at P<.05.

# RESULTS

#### **Sample Characteristics**

A total of 1161 employed parents of CSHCN (372 in Wave 1, 396 in Wave 2, 393 in Wave 3) completed interviews (Table 1). The average age was 40.3 years; 62% were female; 45% were white non-Hispanic, 36% Hispanic, 5% black non-Hispanic, and 14% other; and 36% had a college degree.

Seventy-five percent were employed full-time, 76% had a spouse or partner, and 45% had a spouse or partner employed full-time. Thirty-seven percent reported providing all or most of the childcare (primary caregiver), 30% about half (co-primary caregiver), and 33% some or none (secondary caregiver). Primary caregivers were mostly female (85%), while secondary caregivers were mostly male (65%). Primary caregivers were less likely to have a spouse or partner than secondary caregivers (67% vs. 90%, P<.001). Although 64% of parents reported access to sick leave or vacation through their employer, only 38% reported access to sick leave and vacation (almost all of these parents reported access to unpaid FMLA leave.

The average age of CSHCN in our sample was 9.0 years. On average, these children had pediatric quality-of-life scores of 67.6/100, as well as 1.4 hospital admissions and 10.2 hospital nights in the past year.

#### **Childcare Responsibilities and Access to Leave**

In bivariate logistic regressions, greater self-reported childcare responsibilities were associated with less access to leave benefits (Table 2). Although 82% of secondary caregivers reported access to sick leave or vacation, only 65% of primary caregivers reported such access (P<.001). Similarly, more secondary than primary caregivers reported access to paid leave outside of sick leave and vacation (51% vs. 41%, P<.05); and more secondary caregivers than primary caregivers were eligible for FMLA leave (44% vs. 28%, P<.001).

Despite reporting less access to leave benefits, primary caregivers remained equally as likely as secondary caregivers to miss any work in the past year to care for their ill child and to report being unable to miss work despite needing to do so (not shown). Instead, primary caregivers were more likely than secondary caregivers to miss >4 weeks of work (OR 1.60, P<.05), more likely to be employed part-time rather than full-time (OR 2.86, P<.001, not shown), and far more likely to be women than men (OR 10.8, P<.001). Among Wave 2 and Wave 3 parents, caregiver status was not associated with awareness of PFLI (not shown).

#### **Multivariate Regressions**

In multivariate logistic regressions controlling for parent and child demographics, parent employment characteristics, and child health measures, primary childcare responsibilities were still associated with less access to sick leave or vacation (P<.05) but not FMLA eligibility or access to paid leave outside of sick leave and vacation (Table 3).

In secondary analyses, we explored why the strong bivariate association between greater childcare responsibilities and less access to paid leave disappeared in multivariate regressions. Much of this bivariate association was explained by the correlations of female gender and part-time employment with both greater childcare responsibilities and less access to paid leave (not shown).

In multivariate regressions, being employed part-time was strongly associated with less access to sick leave or vacation and less FMLA eligibility but not less access to paid leave outside of sick leave and vacation (Table 3). We examined the possibility that associations between childcare responsibilities and access to leave benefits differed between parents employed part-time and parents employed full-time. Interactions between employment status and childcare responsibilities, however, were not significant (not shown).

With respect to the other covariates, greater education was generally associated with greater access to all three benefits. Both eligibility for overtime pay and greater household income were associated with greater access to sick leave or vacation and greater eligibility for FMLA leave, but not greater access to paid leave outside of sick leave and vacation (Table 3).

## DISCUSSION

This study is the first to show that access to family leave benefits among parents of CSHCN is skewed away from primary caregivers and toward secondary caregivers. The health policy importance of this finding is clear. In our sample, government and employer-provided benefits appeared to favor those employees who were either less likely to need them or less equipped to take advantage of them. Meanwhile, primary caregivers, who presumably have more incentive to miss work to care for their sick children and more experience providing that care, were often left without substantial access to leave benefits. This disparity was explained in part by the higher likelihood of primary caregivers to be female and part-time employed.

Some of this disparity in access is likely attributable to self-selection. Primary caregivers might choose jobs that are already designed to allow time off without the need for formal benefits. Part-time employment, for instance, could be one such choice, as might adopting relatively traditional gender roles (which, in our analyses, cannot be disentangled from non-self-selection issues such as gender equity). However, our multivariate regressions continued to demonstrate a robust association between greater childcare responsibilities and less access to sick leave and vacation. These regressions included parent gender, as well as part-time employment and job status proxies such as overtime eligibility and supervisory responsibilities, suggesting that self-selection is only a partial mediator at best. Moreover, the associations we observed between caregiver status and any of our outcomes did not vary based on whether a parent was employed full-time or part-time. Nevertheless, future studies should also include more direct measures of job flexibility as covariates.

In light of these associations, the fact that primary caregivers reported no differences from secondary caregivers with respect to missed work is somewhat disquieting. It would suggest

that primary caregivers are continuing to miss work to care for their children, but that many are doing so without the help of leave benefits, which could translate to a greater risk of experiencing financial or emotional burdens when they do miss work, especially when the foregone benefit is one that would have provided pay (e.g., PFLI). Moreover, the fact that primary caregivers were no more likely to have heard of PFLI than secondary caregivers confirms that the previously reported dissemination failure of this potentially important benefit was widespread, including even the most vulnerable sub-populations.<sup>15</sup>

The study has some limitations. The most recent data are from 2008, just prior to the sharp economic downturn that may have altered the family leave benefit landscape. The data are also from CA, which has the oldest and perhaps the most progressive paid family leave law in the country. Both of these limitations, however, suggest that our findings may represent a best-case scenario with respect to access to leave, likely making the lack of access among primary caregivers a national concern.

This study brings to light a potentially compelling justification for reforming the patchwork system of government and employer-provided family leave. Currently, benefits appear to be allocated inefficiently, offered essentially as compensation for employment and performance characteristics that tend to be less common among primary caregivers. In other words, leave benefits flow to the employees who may be least likely to use them, while those who may need benefits most are often shut out. Although our study confirms that women and part-time employees are placed at a disadvantage in this system due to their strong tendency to be primary caregivers, our findings also suggest that being a primary caregiver itself may have independent importance. Being a primary caregiver, for instance, may cause parents to choose jobs whose family-friendly characteristics (e.g., schedule flexibility) are undermined by an absence of benefits. Regardless, broader access to family leave benefits may be needed to reduce this important disparity.

## Acknowledgments

This research was supported by the National Institutes of Health (R21 HD052586), the Centers for Disease Control and Prevention (CDC U48/DP000056), and the California Endowment.

We thank Mattel Children's Hospital at UCLA for providing administrative data for the study; the RAND Survey Research Group for data collection; the UCLA/RAND Work-Family Advisory Board for advice during questionnaire development; and the UCLA/RAND Center for Adolescent Health Promotion and the Evanston Northwestern Healthcare Research Institute for administrative and research assistance.

#### References

- Bianchi, SM.; Robinson, JP.; Milkie, MA. Changing Rhythms of American Family Life. New York, NY: Russell Sage Foundation; 2006.
- Parker K. The Harried Life of the Working Mother. Pew Research Center, Social and Demographic Trends. 2009 Available at: http://pewsocialtrends.org/2009/10/01/the-harried-life-of-the-workingmother/.
- Bureau of Labor Statistics. [Accessed June 20, 2011] Employment Characteristics of Families in 2008. Bureau of Labor Statistics, United States Department of Labor. 2009. Available at: http:// www.bls.gov/news.release/archives/famee\_05272009.pdf
- 4. Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. Pediatrics. 1998; 102:117–123. [PubMed: 9651423]

- 5. American Academy of Pediatrics. Family-centered care and the pediatrician's role. Pediatrics. 2003; 112(3 Pt 1):691–697. [PubMed: 12949306]
- Johnson CP, Kastner TA. Helping families raise children with special health care needs at home. Pediatrics. 2005; 115:507–511. [PubMed: 15687462]
- Smith LA, Romero D, Wood PR, Wampler NS, Chavkin W, Wise PH. Employment barriers among welfare recipients and applicants with chronically ill children. Am J Public Health. 2002; 92:1453– 1457. [PubMed: 12197972]
- 8. Thyen U, Kuhlthau K, Perrin JM. Employment, child care, and mental health of mothers caring for children assisted by technology. Pediatrics. 1999; 103:1235–1242. [PubMed: 10353935]
- Cantor, D.; Waldfogel, J.; Kerwin, J., et al. Balancing the Needs of Families and Employers: Family and Medical Leave Surveys. Rockville, MD:: Westat, United States Department of Labor; 2001.
- Han WJ, Waldfogel J. Parental leave: the impact of recent legislation on parents' leave taking. Demography. 2003; 40:191–200. [PubMed: 12647520]
- 11. California Paid Leave Law, S1661. 2002
- 12. Washington Paid Leave Law, S5659, 60th Leg. 2007
- 13. New Jersey Paid Leave Law, S786/A873, 213th Leg. 2008
- 14. Accrued Sick and Safe Leave Act, DC Law 17–152. 2008
- Schuster MA, Chung PJ, Elliott MN, Garfield CF, Vestal KD, Klein DJ. Awareness and use of California's paid family leave insurance among parents of chronically ill children. JAMA. 2008; 300:1047–1055. [PubMed: 18768416]
- Chung PJ, Garfield CF, Elliott MN, Carey C, Eriksson C, Schuster MA. Need for and use of family leave among parents of children with special health care needs. Pediatrics. 2007; 119:e1047– e1055. [PubMed: 17473078]
- Schuster MA, Chung PJ, Elliott MN, Garfield CF, Vestal KD, Klein DJ. Perceived effects of leave from work and the role of paid leave among parents of children with special health care needs. Am J Public Health. 2009; 99:698–705. [PubMed: 19150905]
- National Association of Children's Hospitals and Related Institutions. All Children Need Children's Hospitals. 2nd Ed.. Alexandria, VA: National Association of Children's Hospitals and Related Institutions; 2007.
- International Classification of Diseases. Ninth Revision. Geneva, Switzerland: World Health Organization; 1980.
- Ferris TG, Perrin JM, Manganello JA, Chang Y, Causino N, Blumenthal D. Switching to gatekeeping: changes in expenditures and utilization for children. Pediatrics. 2001; 108:283–290. [PubMed: 11483789]
- Hwang W, Ireys HT, Anderson GF. Comparison of risk adjusters for medicaid-enrolled children with and without chronic health conditions. Ambul Pediatr. 2001; 1:217–224. [PubMed: 11888404]
- Kuhlthau KA, Beal AC, Ferris TG, Perrin JM. Comparing a diagnosis list with a survey method to identify children with chronic conditions in an urban health center. Ambul Pediatr. 2002; 2:58–62. [PubMed: 11888439]
- Perrin JM, Kuhlthau K, McLaughlin TJ, Ettner SL, Gortmaker SL. Changing patterns of conditions among children receiving Supplemental Security Income disability benefits. Arch Pediatr Adolesc Med. 1999; 153:80–84. [PubMed: 9895004]
- Muldoon JH, Neff JM, Gay JC. Profiling the health service needs of populations using diagnosisbased classification systems. J Ambul Care Manage. 1997; 20:1–18. [PubMed: 10181610]
- Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of medical charges for children by health status group and severity level in a Washington State Health Plan. Health Serv Res. 2004; 39:73–89. [PubMed: 14965078]
- Neff JM, Sharp VL, Muldoon J, Graham J, Popalisky J, Gay JC. Identifying and classifying children with chronic conditions using administrative data with the clinical risk group classification system. Ambul Pediatr. 2002; 2:71–79. [PubMed: 11888441]

- Gay JC, Muldoon JH, Neff JM, Wing LJ. Profiling the health service needs of populations: Description and uses of the NACHRI Classification of Congenital and Chronic Health Conditions. Pediatr Ann. 1997; 26:655–663. [PubMed: 9397444]
- 28. American Association for Public Opinion Research. AAPOR outcome rate calculator version 2.1. 2008 Available at: http://www.aapor.org/Do\_Response\_Rates\_MatteR\_/2856.htm.
- Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL in type 1 and type 2 diabetes: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales and type 1 Diabetes Module. Diabetes Care. 2003; 26:631–637. [PubMed: 12610013]
- 30. Little, R.; Rubin, D. Statistical Analysis with Missing Data. New York, NY: Wiley & Sons; 1987.
- 31. Royston P. Multiple imputation of missing values. Stat Journal. 2004; 4:227–241.
- 32. Hosmer DW, Hosmer T, Le Cessie S, Lemeshow S. A comparison of goodness-of-fit tests for the logistic regression model. Stat Med. 1996; 16:965–980. [PubMed: 9160492]
- Chan KS, Mangione-Smith R, Burwinkle TM, Rosen M, Varni JW. The PedsQL: reliability and validity of the short-form generic core scales and Asthma Module. Med Care. 2005; 43:256–265. [PubMed: 15725982]

## WHAT'S NEW

This study is the first to show that access to family leave benefits among parents of CSHCN is skewed away from primary caregivers and toward secondary caregivers, even though primary caregivers are as likely to miss work to provide care.

# Table 1

# Weighted Characteristics of Employed Parents of CSHCN

Parent Demographic Variables	Total (n=1,161)	Wave 1 (n=372)	Wave 2 (n=396)	Wave 3 (n=393)
Childcare responsibilities (%)				
All/most (Primary caregiver)	36.7	32.9	40.0	37.1
About half (Co-primary caregiver)	29.7	32.4	26.8	30.1
Some/none (Secondary caregiver)	33.6	34.7	33.2	32.8
Employed part-time (%)	25.1	21.9	25.2	28.2
Spouse/partner employment status (%)				
Spouse/partner employed full-time	45.4	43.1	47.2	46.0
Spouse/partner employed part-time	10.0	10.8	10.2	9.1
Spouse/partner not employed	20.3	24.3	16.3	20.6
No spouse/partner	24.0	21.0	26.3	24.3
Other non-spouse/partner adults in household (mean, SD)	0.5 (0.9)	0.5 (0.9)	0.5 (1.0)	0.4 (0.8)
Other children in household (mean, SD)	1.2 (1.2)	1.3 (1.2)	1.3 (1.3)	1.1 (1.1)
Age in years (mean, SD)	40.3 (8.4)	39.5 (7.6)	41.1 (8.7)	40.1 (8.6)
Female gender (%)	62.0	59.3	63.8	62.7
Race/Ethnicity (%)				
White non-Hispanic	44.9	44.5	40.9	49.4
Hispanic	35.9	38.8	38.0	31.0
Black non-Hispanic	5.3	6.1	5.7	4.0
Other	13.9	10.6	15.4	15.6
Education (%)				
High school degree or less	31.3	31.3	33.8	28.8
Some college, no degree	32.5	35.5	30.2	32.2
College degree or more	36.1	33.2	36.1	39.0
Household Income (%)*				
\$0-\$19,999	17.9	21.1	19.4	13.4
\$20,000-\$49,999	25.5	28.2	25.0	23.5
\$50,000-\$99,999	29.2	27.0	29.3	31.1
\$100,000-\$149,999	14.3	12.0	15.5	15.3
\$150,000	13.1	11.8	10.8	16.6
Parent Employment-Related Variables				
Eligible for overtime pay (%)	44.3	43.8	40.8	48.3
Supervises 2 people at place of employment (%)	33.8	34.5	34.3	32.6
Access to sick leave or vacation (%)	73.3	76.6	73.8	69.7
Access to paid leave (not including sick leave and vacation) (%)	46.2	48.0	43.1	47.7
Eligible for FMLA leave (%)	37.6	37.7	38.2	36.8
Child Demographic Variables				

Parent Demographic Variables	Total (n=1,161)	Wave 1 (n=372)	Wave 2 (n=396)	Wave 3 (n=393)
Female gender (%)	49.8	50.2	49.1	50.1
Child age (years, SD)	9.0 (5.6)	8.9 (5.4)	9.5 (5.6)	8.7 (5.8)
Child <2 years old (%)	12.3	12.4	11.7	13.0
PedsQL score 0–100 (mean, SD)**	67.6 (23.3)	67.2 (23.0)	64.4 (24.7)	71.3 (21.6)
Hospital admissions in past year (mean, SD)	1.4 (4.1)	1.7 (4.3)	1.2 (2.7)	1.4 (5.1)
Hospital nights in past year (mean, SD)	10.2 (27.4)	12.8 (29.1)	8.8 (25.5)	9.1 (27.6)

\* P<.05,

\*\* *P*<.01. Bivariate analyses conducted using linear regression for continuous variables, ordered logistic regression for multicategory variables, logistic regression for dichotomous variables, and design-based F-test for categorical variables.

# Table 2

Bivariate Logistic Regressions and Predicted Probabilities (n=1,161)

	Access to sick leave or vacation	or vacation	Access to paid leave (not including sick leave and vacation)	leave (not leave and n)	Eligible for FMLA leave	LA leave
	OR (95% CI)	Probability	OR (95% CI) Probability OR (95% CI) Probability	Probability	OR (95% CI)	Probability
Childcare responsibilities						
Some/none (Secondary caregiver)	Reference	82	Reference	51	Reference	44
About half (Co-primary caregiver) 0.64 (0.39–1.06)	0.64 (0.39–1.06)	74	0.88 (0.61–1.26)	48	0.95 (0.67–1.35)	43
All/most (Primary caregiver)	$0.42 (0.27 - 0.65)^{***}$	65	$0.67 (0.47 - 0.94)^{*}$	41	0.48 (0.34–0.68)***	28

\*\*\* P<.001. Bivariate analyses were conducted as logistic regressions.

#### Table 3

Multivariate Logistic Regressions (n=1,161)

Independent Variables	Access to sick leave or vacation	Access to paid leave (not including sick leave and vacation)	Eligible for FMLA leave
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Childcare responsibilities			
Some/none (Secondary caregiver)	Reference	Reference	Reference
About half (Co-primary caregiver)	0.59 (0.33–1.08)	0.90 (0.60–1.35)	1.14 (0.75–1.72)
All/most (Primary caregiver)	0.42 (0.21–0.82)*	0.83 (0.52–1.34)	0.67 (0.41–1.09)
Employed part-time (vs. full-time)	0.16 (0.10–0.26)***	0.56 (0.37–0.86)**	0.18 (0.10–0.32)**
Spouse/partner employment status			
Spouse/partner employed full-time	Reference	Reference	Reference
Spouse/partner employed part-time	0.69 (0.33–1.46)	1.50 (0.90–2.49)	1.11 (0.62–1.97)
Spouse/partner not employed	1.00 (0.50–1.98)	1.31 (0.84–2.05)	1.20 (0.77–1.86)
No spouse/partner	1.06 (0.56–2.00)	1.33 (0.85–2.08)	1.36 (0.83–2.22)
Other non-spouse/partner adults in household	0.77 (0.57, 1.04)	1.04 (0.82–1.06)	1.04 (0.82, 1.31)
Other children in household (number)	0.91 (0.75–1.10)	0.93 (0.82–1.06)	1.03 (0.90–1.17)
Eligible for overtime pay	2.63 (1.68–4.12)***	0.97 (0.70–1.35)	1.74 (1.24–2.44)**
Supervises 2 people at place of employment (yes/no)	2.61 (1.62–4.21)***	1.15 (0.85–1.54)	1.08 (0.76–1.54)
Age (per SD)	0.93 (0.70–1.23)	1.09 (0.89–1.33)	1.18 (0.94–1.50)
Female gender	1.56 (0.87–2.80)	1.22 (0.82–1.83)	1.03 (0.69–1.54)
Race/Ethnicity			
White non-Hispanic/Latino	Reference	Reference	Reference
Black non-Hispanic/Latino	0.79 (0.20–3.16)	0.72 (0.35–1.50)	1.90 (0.86-4.22)
Hispanic/Latino	1.07 (0.60–1.92)	1.26 (0.84–1.90)	1.26 (0.82–1.91)
Other	1.02 (0.59–1.77)	0.86 (0.57–1.29)	1.06 (0.68–1.66)
Education			
High school degree or less	Reference	Reference	Reference
Some college	2.53 (1.40–4.57)**	1.77 (1.11–2.82)*	1.84 (1.12–3.05)*
College degree or more	2.75 (1.48–5.11)**	1.68 (1.02–2.76)*	2.35 (1.38–3.99)**
Household Income			
\$0-\$19,999	Reference	Reference	Reference
\$20,000-\$49,999	2.84 (1.41–5.72)**	1.74 (0.95–3.16)	1.69 (0.84–3.42)
\$50,000-\$99,999	2.67 (1.28–5.56)**	1.40 (0.75–2.60)	3.11 (1.47–6.55)**
\$100,000-\$149,999	2.36 (1.02–5.48)*	2.10 (1.06–4.19)*	3.90 (1.69–9.00)**
\$150,000	1.69 (0.70-4.05)	2.20 (1.08–4.48)*	3.24 (1.36–7.71)**
PedsQL score (per SD)	1.21 (0.98–1.48)	1.23 (1.05–1.45)*	0.80 (0.68–0.95)**
Child <2 years old	0.79 (0.37–1.72)	1.43 (0.85-2.42)	1.47 (0.83-2.62)

Independent Variables	Access to sick leave or vacation	Access to paid leave (not including sick leave and vacation)	Eligible for FMLA leave
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Child age (years)	0.97 (0.92–1.03)	1.00 (0.96, 1.04)	0.99 (0.95, 1.04)
Hospital admissions in past year (number)	1.02 (0.96, 1.09)	1.00 (0.95, 1.05)	0.97 (0.90, 1.05)
Hospital nights in past year (number)	1.00 (0.99, 1.01)	1.00 (0.99, 1.00)	1.00 (0.99, 1.00)
Wave			
Wave 1	Reference	Reference	Reference
Wave 2	1.08 (0.66–1.77)	0.83 (0.58–1.20)	0.98 (0.67–1.42)
Wave 3	0.62 (0.38–1.02)	0.92 (0.64–1.32)	0.91 (0.62–1.34)

CI = confidence interval, OR = odds ratio.

\* P<.05

\*\* P<.01

\*\*\* P<.001