Washington Center for Equitable Growth

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Paid Leave RESEARCH ACCELERATOR

Paid family and medical leave in the United States

A data agenda

March 2019 Amy Batchelor

Equitable Growth

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Overview

The United States continues to be an outlier among developed countries for its lack of a national paid leave program. New parents across our nation struggle to balance the demands of their jobs with the needs of their families. And the necessity of paid leave only escalates as the U.S. population ages and more spouses and parents find themselves in need of support to recover from an illness or injury, or to maintain independence in their communities.

Existing paid leave benefits do not reach everyone. For low-income workers (in the lowest quartile) less than 10 percent have access to paid family leave.[1] Too many families are being left out, unable to access benefits that can help them meet the needs of their families and their employers.

Understanding the programs that exist in states is an important step on the pathway to a national program. California, New Jersey, and Rhode Island have had state paid leave programs for years. And since 2017, three new states (New York, Washington, and Massachusetts) and the District of Columbia have all passed paid family and medical leave laws. Important academic research and policy analysis has been done using data from these programs to understand how paid leave affects workers, families, and employers in these states. Yet there are still a number of outstanding questions about how paid family and medical leave functions in the United States.

In a report issued in 2018, the Washington Center for Equitable Growth reviewed the existing evidence and outlined remaining questions comprising a research agenda for paid family and medical leave.[2] That report provided a framework for understanding the various channels through which paid leave affects economic outcomes via individual-level health and employment outcomes, firm-level and employee outcomes, and broader macroeconomic impacts.

Compelling evidence exists in each of these channels, suggesting there is an important positive role for paid family and medical leave. But real gaps remain in the knowledge, especially regarding paid leave for one's own medical needs, as well as caregiving leave. These open questions fall into two broad categories. The first category includes knowledge gaps where data are available that could be marshalled to answer questions. The second, and trickier, category includes knowledge gaps that require the collection of new data or expanded access to existing data to answer research questions.

This follow-up report assesses the state of the data available for answering those remaining questions. It then provides a roadmap for building the necessary data in order to generate evidence-backed policy. The report will focus on a set of key questions raised from the previous report. Specifically, it will examine:

- The data that currently exist
- Barriers to accessing those data
- Pathways to removing those barriers

This report is based on both a survey of the data landscape, as well as the insights shared at a day-long event hosted by the Washington Center for Equitable Growth. Follow-up interviews with participants were then conducted, including with leading scholars of paid family and medical leave, state administrators from states that already have or are in the process of implementing paid leave programs, federal data experts, and researchers in associated fields, including public health and disability policy.

Existing datasets have a lot to offer toward better understanding paid family and medical leave policies, but uncertainty remains about whether data exists to answer critical questions. The content outlined in this report builds on the themes of the event to flesh out a data agenda that could move the issue of paid family and medical leave forward by providing the necessary raw material for answering important unanswered questions.

The remainder of this report is organized into specific topics. It begins with a discussion of the existing types of data available to study paid family and medical

leave. Then, in each of the subsequent sections, a different component of paid family and medical leave is examined:

- Parental leave: leave taken by either parent for bonding with a new baby, whether after a birth or an adoption
- Medical leave: leave taken to recover from a serious personal illness or injury that requires leave longer than a few days
- Caregiving leave: leave taken to care for an ill or injured family member other than a new baby
- Demographic issues across all types of leave
- Firm effects across all types of leave
- Interactions with existing state and federal programs across all types of leave

For each type of leave, key questions from the initial report will be highlighted, followed by a short summary of existing data relevant to those questions. Each section includes an analysis of gaps in the existing data and suggestions for future data collection or improvements in data access that would allow for additional research in each area. In conclusion, the report will summarize a data agenda that would provide the tools necessary to strengthen the literature on paid family and medical leave.

Existing data

There are three primary sources of data on paid family and medical leave: survey data from nationally representative surveys, administrative data collected by government agencies in the process of administering programs, and a category of other data types that range from smaller nonrepresentative surveys to employer data systems to focus groups. There are valuable data in longitudinal surveys such as the Panel Study on Income Dynamics, or PSID (compiled since 1968 by the University of Michigan's Institute for Social Research), the National Health and Aging Trends Study, or NHATS (led by Johns Hopkins University Bloomberg School of Public Health since 2011), and the Health and Retirement Survey, or HRS (compiled by the University of Michigan since 1990). All three of these datasets help capture some data on paid leave, as well as long-term health and employment outcomes, by following the same sample of people over an extended period of time.

Yet these surveys have been limited either by a lack of focus on paid leave or the length of time the survey has existed. Neither PSID nor HRS have specific questions about the need for or use of paid leave and while NHATS collects detailed information about the need for caregiving among older adults, it has only been underway since 2011.

Cross-sectional surveys or those that have a shorter follow-up period include the U.S. Census Bureau's Current Population Survey, or CPS, and the Survey of Income and Program Participation, or SIPP, as well as the U.S. Bureau of Labor Statistics' National Compensation Survey, or NCS, and the American Time-Use Survey, or ATUS. These federal datasets capture characteristics of the population using paid leave and the take-up rates of programs but cannot capture the long-term effects of program participation on the participants or the unmet need for leave.

CPS has a long history of data collection but is limited to a reference week that might not capture the many ways that workers use short-term leave. ATUS has

a detailed leave module from 2011, but outside of the module, the questions associated with leave-taking are limited to employment, earnings, and whether the person has provided eldercare. SIPP includes a fertility module that provides detailed retrospective information on leave taken after the birth of a child but does not contain leave data beyond that of maternity leave for mothers who gave birth to a new baby.

Despite the shortcomings of the available survey data from these large national samples, they offer useful data for analyzing these programs. Importantly, the largest omission in these surveys is data on those who need leave but are not taking it. Survey data can capture individuals who report taking leave and administrative data can capture those individuals who receive benefits while on leave, but both of these sources are inadequate to describe the unmet need for leave.

The Department of Labor Family and Medical Leave Act Worksite and Employee Survey—referred to as the DOL FMLA survey—conducted in 1995, 2000, and 2012 is likely the best source for describing the unmet need for leave among employees. By asking about need for leave regardless of ability to take the leave, these surveys find potentially eligible individuals who are difficult to identify. Survey data can infer the need for parental leave among individuals who have had a child but do not have questions in place to capture potential need to care for a personal illness or injury or to care for another family member. Additional waves of this survey would provide needed insights into those missed by policies and programs meant to support family caregivers.

The second major sources of data on paid leave is administrative data. Administrative data, collected by the government in the process of operating programs and providing benefits, is a rich and currently underutilized resource. States collect information on program applicants and participants as part of running their programs in order to determine eligibility and monitor participation and progress toward desired outcomes. Administrative data may not have the rich detail of some of the survey data available—in particular, it often lacks detailed demographic information if it is not relevant to an eligibility determination process. But these data hold the potential to understand who uses the program and for what purposes.

If administrative data is linked to data on employment and health, which is also captured by other government agencies and programs, then together those data can show the effects of program use as well. Administrative data, particularly

for states that have already had paid leave programs in place, is very difficult but not impossible to access. Summary statistics are available online for programs in California, New Jersey, and Rhode Island, but getting individual-level data is nearly impossible either because of privacy protections that limit the disclosure of data, technical barriers caused by antiquated information technology systems, or a combination of the two.

Beyond nationally representative surveys and administrative data lies an assortment of different types of data that vary in their focus, type, and scope. Qualitative studies make use of surveys of small samples for in-depth analysis of experiences with family and medical leave, focus groups of underrepresented groups, data collected on employee performance and retention, among others data sources. These smaller samples and deeper dives into individual or group experiences provide details about specific aspects of caregiving experiences that are difficult to capture in a few survey questions. The small sample sizes limit the potential for analysis and extrapolation to the larger population, but still provide necessary context for understanding the lived experience of people who need leave, their caregivers, families, and employers.

Each of the following sections will describe a different aspect of paid family and medical leave using the data sources that have been used to analyze them and will highlight gaps in the data that could allow for additional analysis and suggest pathways to better data in the future.

Data sources for researching paid family leave

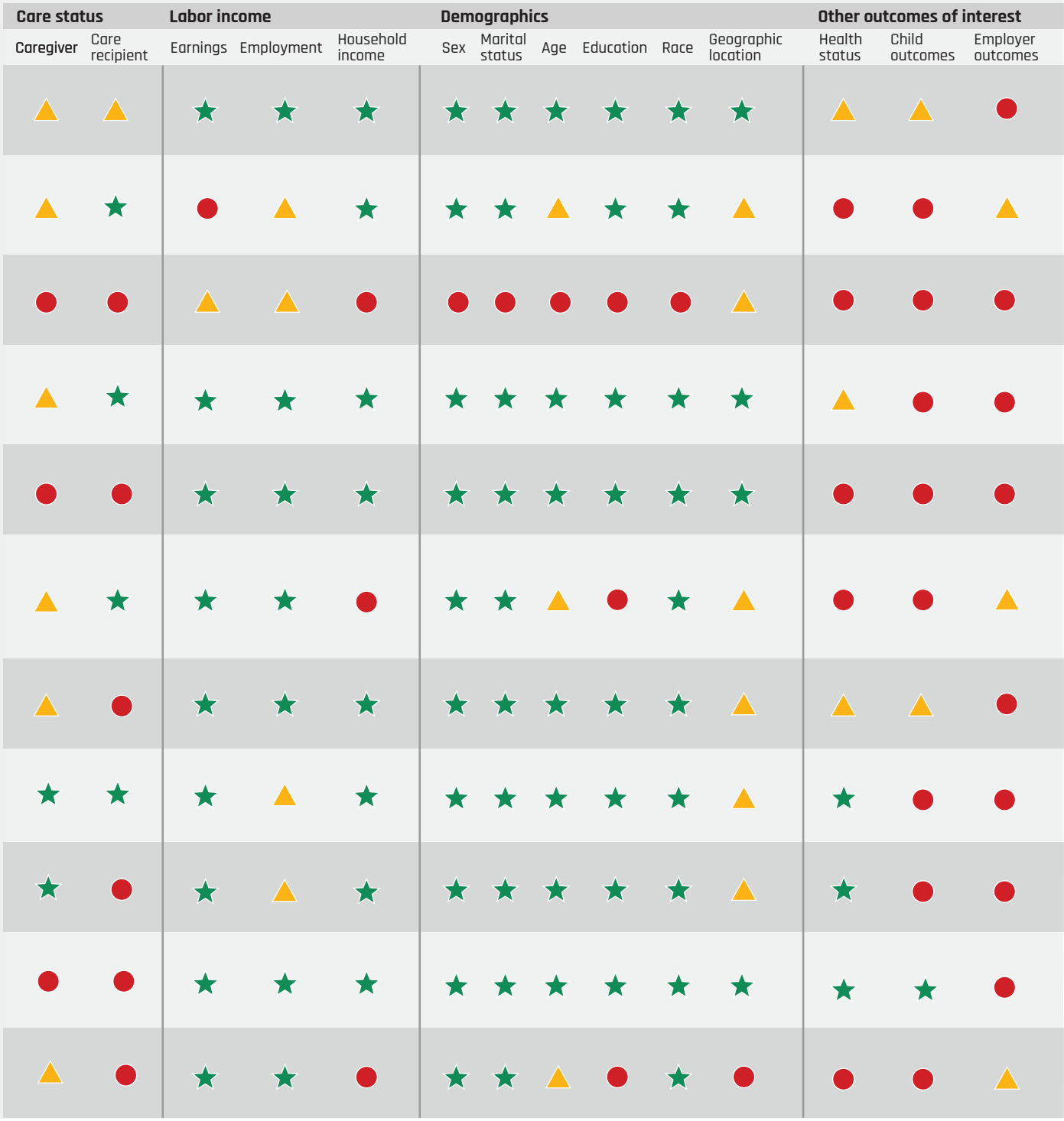
The eleven most relevant data sources ranked by usefulness to researchers across seven major categories

★ **Excellent:** High level of detail available across years

▲ **Uneven:** Variable coverage across years, inconsistent definitions, over-broad categories, restricted use

● **Poor:** No available data or data quality too inconsistent/broadly defined to be useful

Data set	Owner/access	Sample details		Leave		
		Date(s)	Sample size (approximate)	Take-up	Wage replacement	Duration
Survey of Income and Program Participation (SIPP)	U.S. Census Bureau, mix of public-use and restricted access	1984-2014 4-year panels	37,000-100,000 (varies by panel)	▲	●	●
FMLA Worksite and Employee Surveys (DOL FMLA)	U.S. Department of Labor, limited years of public use files	1995, 2000, 2012 worksite and employee cross-sections	2,000	▲	●	●
National Compensation Survey – Employee Benefits Survey (NCS)	U.S. Bureau of Labor Statistics, public use files availables	2010-2017 establishment surveys	11,000	★	●	●
American Time Use Survey (ATUS)	U.S. Bureau of Labor Statistics, limited public use files available	2003-2017 cross-sections	11,000	▲	●	●
Current Population Survey (CPS) Annual Social and Economic Supplemental Resarch Files (ASEC)	U.S. Census Bureau/Bureau of Labor Statistics, microdata available from January 1994	1994-2017 cross-sections (can match to create two-year panels)	60,000	▲	●	●
Health and Retirement Study (HRS)	Institute for Social Research at the University of Michigan, public use and restricted data available via secure remote connection	1992-2014 panel study of community-dwelling 50+ year-olds (respondents are retained if participant enter into nursing home care)	6,000-12,000 (varies by panel)	●	●	●
Panel Study of Income Dynamics (PSID)	University of Michigan, publicly available to university-affiliated scholars	1968-2017	16,000	●	●	●
National Health and Aging Trends Study (NHATS)	Johns Hopkins Bloomberg School of Public Health, public use files available with registration	2011-2017 panel study of 65+ year old Medicare enrollees	8,000	●	●	●
National Study of Caregiving (NSOC)	Johns Hopkins Bloomberg School of Public Health, public use files available with registration	2011-2017 cross-section of NHATs respondents' family caregivers	2,000	▲	●	●
National Survey of America's Families (NSAF)	Urban Institute, limited public use files available	1997, 1999, 2002 cross-sections	110,000	▲	●	●
Viewpoints on Paid Family and Medical Leave	Ernst+Young, proprietary	2016	1,500 HR professionals + 3,000 employees	▲	●	●


Care status
Caregiver
Care recipient
Labor income
Earnings
Employment
Household income
Demographics
Sex
Marital status
Age
Education
Race
Geographic location
Other outcomes of interest
Health status
Child outcomes
Employer outcomes

Paid parental leave

Key remaining questions

- How does the impact of paid parental leave on individual labor market outcomes (job retention, labor force participation, hours worked, wages) vary by gender over time?
- Does access impact the gender wage gap over time?
- Do male take-up rates and leave durations affect women's labor market outcomes?
- How do different elements of parental leave policy design drive labor market outcomes (job retention, labor force participation, hours worked, wages)?
- What are the causal pathways through which parental leave affects maternal and child health across the life cycle?

Data used in current research

Data available on parental leave and bonding is the richest among the types of leave discussed in this paper. Many datasets capture the birth of a child and the time directly preceding and following a birth. This "bright line" event makes research on parental leave easier, particularly for leave related to a mother's physical recovery from giving birth. This type of leave also has been available for much longer than the newer paid family leave programs, allowing for long-term analysis or labor market and health outcomes.

Labor market outcomes

Many of the major longitudinal studies make it possible to study labor market outcomes for women after the birth of a child and capture information about the availability or use of leave following a birth. Previous research on labor market outcomes for parental leave have focused heavily on maternal labor force attachment, particularly because state temporary disability benefits have been available to women for physical recovery from the birth of a child for longer than parental

leave programs that promote bonding and are available to mothers, fathers, and adoptive parents.

To study the labor market effects of the California paid family leave program, Maya Rossin-Slater at Stanford University's School of Medicine, Christopher Ruhm at the University of Virginia's Frank Batten School of Leadership and Public Policy, and Jane Waldfogel at Columbia University's School of Social Work used the Current Population Survey to look at weekly work hours for employed mothers of 1- to 3-year-old children before and after the enactment of the program.[3] The National Longitudinal Survey of Youth also has been used to study labor force attachment for women and the use of public benefits after the birth of a child.[4]

Date from the Survey of Income and Program Participation on retrospective fertility, employment, and maternity leave data has been used to study the experience of women around a birth. Using these data, researchers have studied work experience prior to a first birth, factors associated with employment during pregnancy, and whether a woman returned to the same employer she had during pregnancy after a birth.[5] Similar work with SIPP was done to analyze the effects of short-duration paid parental leave on maternal labor supply.

This research estimated the effects of paid leave laws in California and New Jersey on women's labor force outcomes around a birth.[6] The Panel Study of Income Dynamics can also be used for this type of analysis on return to work, and has previously been merged with additional data at the state level to control for labor market opportunities for women. In one study, the state-level employment information for women was taken from the Current Population Survey's Merged Outgoing Rotation Groups to add to the analysis available through the PSID.[7]

These studies are limited in their possible applications for long-term labor market outcomes. While both are longitudinal, the maximum observation window is only 4 years for SIPP and 2 years for CPS. While semi-longitudinal studies can be done, their scope is limited by these short durations. The National Longitudinal Survey of Youth offers the chance for long-term outcomes on employment and health, but the 1997 panel was at most age 36 in 2015–2016, when the most recent data was collected. For these data, doing long-term analysis is possible but it will take time for the effects to reveal themselves.

From administrative data, a few states have temporary disability programs that cover pregnancy-related leave and have existed long enough to study long-term effects. The newer paid family leave programs or caregiver insurance have not been in place as long, though unlike temporary disability programs, they are accessible not just to a birth mother but also to fathers, adoptive parents, and caregivers for other members of a family. As these policies are in place for longer periods of time, researchers will be able to start evaluating the long-term outcomes for employment and earnings among men and women who took bonding leave after the birth of a child. But in order to be able to study the effects of leave-taking on fathers and adoptive parents, administrative data needs to be accessible—which it is not at this time because of technical challenges and a lack of clear procedures for researchers to access data or clear barriers for access meant to protect the privacy of program participants.

It is possible to do some analysis of leave-taking for fathers using large national surveys, but there are significant challenges. Household surveys are generally poorly suited to identifying use of leave unless specific questions about leave over the course of months or a year is captured. Most surveys ask about employment status in a given specific reference week, and so the window for capturing leave is small and may miss the typically short leaves taken by fathers. Surveys such as the fertility supplement for the Survey of Income and Program Participation, which captures detailed information about mother's leave-taking, do not ask about fathers' leave-taking.

Some basic comparative data on wage gaps in countries with more generous paid leave policies point to a possible inverse relationship between leave and the gender wage gap.[8] Other studies have used SIPP and data from the Social Security Administration Detail Earnings Records, or SSA-DER, to look at the pay gap around the birth of a child, estimating that in the absence of paid leave, the earnings gap between male and female spouses doubles between 2 years before a birth and the year after a birth.[9] Still others tackle the wage gap using microdata from the U.S. Census Bureau and the American Community Survey.[10] These studies do not specifically tackle the wage gap in states where paid family leave policies have been put in place. But they do offer an approach to apply to states where paid leave may have an effect on gender wage gaps.

Health outcomes

As is true for labor outcomes associated with parental leave, the data around maternal and child health is easier to work with because of the more easily identifiable need for leave that is associated with the birth of a child.

In addition to data captured in surveys such as SIPP and CPS, there are additional surveys that focus on health, including maternal and child health. The Centers for Disease Control and Prevention's Vital Statistics data can be used to examine birth weight, likelihood of a premature birth, and infant mortality for children based on the use of leave. Studies using this data have found maternity leave led to small increases in birth weight, decreases in the likelihood of a premature birth, and substantial decreases in infant mortality.

These results were not distributed evenly but were concentrated for children of college-educated and married mothers, who had the most access to or ability to take leave.[11] Other surveys, among them the National Maternal and Infant Health Survey, also have additional detail on health-related variables around maternity leave and health. While datasets such as these provide excellent information about health impacts following a birth, they do not include information beyond the birth of a child or, in the case of Vital Statistics, have primarily focused on these health outcomes.

Data needs and a path forward

The evidence-based data analysis in the academic literature on the effects of paid parental leave on mothers is strong and positive. And the data to examine these effects are relatively plentiful. Less clear is the relationship of leave on the gender pay gap and men's outcomes. This gap is partially driven by a lack of data from low take-up rates of leave among fathers.

Developing samples of dual-earner households where the secondary caregiver did or did not take leave could offer insights into the effects of leave-taking within a household and the employment trajectory for each individual in the household in a way that is not currently captured in the larger, nationally representative surveys. These samples, even if small, would need to be longitudinal to capture medium- and long-term outcomes but could provide insights into effects of leave by gender.

For researchers to make the most of future possibilities to measure labor market benefits of paid leave, gaining access to administrative data and creating data linkages with employment data through unemployment insurance wage data would allow for analysis of the effects of paid leave on wages and labor force attachment. The use of administrative data and linked data surface repeatedly in this report and an entire section is dedicated to this issue.

With regards to policy design and program structure, an example of possible future work includes looking at areas where local governments have increased the level of benefits compared to state policies. In California, for example, the city and county of San Francisco passed an ordinance that requires employers to ensure that employees who are eligible to receive paid family leave compensation to bond with a new child receive 100 percent of their weekly wage. This provides a case where San Francisco employees are receiving full wage replacement for 6 weeks, while other participants in the state paid leave program are only eligible for 60 percent or 70 percent of their weekly wage.[12] Studying this naturally occurring experiment and the effect of higher replacement rates on individuals within the county of San Francisco and similar cases outside the city and county could provide useful insights into possible program design elements.

Natural experiments such as this one will begin happening more frequently as more states roll out programs with varying designs. While there have been limited attempts to understand the variation in outcomes based on policy designs, more studies like these are necessary to fully grasp the effects of change to different aspects of the policy.

Paid medical leave

Key remaining questions

- How does access to medical leave to care for one's own serious illness affect short-, medium-, and long-term labor market outcomes (job retention, labor force participation, hours worked, wages)?
- What duration of leave do workers typically need for different kinds of illnesses?
- How does leave affect health outcomes and recovery?

Data used in current research

Data to study medical leave is not as readily available as for parental leave. There also is less research on paid medical leave or short-term disability than on sick leave and long-term disability, the latter two of which cover shorter- and longer-term needs for leave, respectively. Paid sick leave is often an accrued benefit paid for by the employer rather than administered by the government, and is frequently considered distinct from both paid medical leave for slightly longer-term illnesses and long-term disability for much longer needs.

Due to a relative dearth of existing literature on paid leave to recover from a personal illness, there are few data sources to discuss. In states that already provide this leave, it was added to their existing temporary disability insurance programs to take advantage of efficiencies in existing infrastructure and expertise. These states (California, Hawaii, New Jersey, New York, and Rhode Island, and the U.S. territory of Puerto Rico) offer a rich opportunity to study the effects of temporary disability insurance on individual, family, and firm-level outcomes.

Data is available to study these short-term leave needs. State administrative data includes lengths of leave, as does some survey data, though it is generally from fairly small sample sizes and may not be from states with a paid family leave

policy.[13] The National Health and Aging Trend Study includes data on time missed from work because of illness but would require differentiating between short illnesses (less than a week) that would generally not be covered by medical leave and longer illnesses that would potentially be covered. The NHATS data also focus on individuals who are over the age of 65, which is a rapidly expanding portion of the population but limits the generalizability of findings for younger cohorts of the U.S. population. The Department of Labor Family and Medical Leave Act survey includes data on the use of leave for own illness, with the largest portion of leave (approximately 55 percent) being used for this purpose. But the DOL FMLA data do not differentiate the duration of leave or number of leave-taking instances by the type of leave taken to provide more detail on the use of medical leave.[14]

The DOL FMLA survey also neither differentiates between types of illnesses that made the leave necessary nor shorter paid leave that would be covered by sick leave rather than medical leave. Administrative and survey data are available but are much less rich than the data available to study maternity leave.

Beyond administrative and representative survey data, there are additional datasets available based on private short-term disability plans. A variety of private short-term disability plans are available. The U.S. Bureau of Labor Statistics estimates that 42 percent of private industry workers had access to short-term disability insurance in 2018, and of those workers, 40 percent are commercially insured.[15] In 2014, BLS estimated that employers were paying, on average, $0.06 per hour for short-term disability insurance for their workers but that most workers do not receive coverage through their employers.[16]

The administrative data from states does not capture the individuals who receive commercial coverage. Private databases—such as MarketScan® Health and Productivity Management and Commercial Claims and Encounters—include information about short-term disability use and absenteeism. These databases have been used to look at the economic effects of specific conditions, among them breast cancer,[17] and could be used for other types of illnesses that frequently result in the need for leave but do not result in long-term disability.

This MarketScan database also includes information about benefit plan enrollment, inpatient and outpatient health care services, pharmaceutical claims, absence records, and claims for short-term disability by workers at several large corporations. But the data do not contain detailed demographic information such as race and ethnicity, and it can be costly to access. When it comes to paid leave, private plans have

received much less attention and could provide a valuable new source of data in this area, even though it is not as clear what pathways exist for data access.

Labor market outcomes

Despite leave-taking by workers to deal with their own illnesses being much more common than for parental or caregiving leave, little is known about the effects of these programs on labor market outcomes. A challenge to understanding the labor market effects of medical leave is that it covers a much wider range of leave-taking needs and behaviors. Unlike parental leave, medical leave is more likely to be intermittent, and the trajectories will vary much more depending on the illness that results in the need for leave. Small samples of data for outcomes from specific groups and specific conditions sheds some light on the labor market outcomes such as job retention, but is limited in its representativeness.[18]

Administrative data could be a useful source for analysis of labor market effects around medical leave. By linking administrative data to wage and employment data it would be possible to follow workers who accessed medical leave to see whether they returned to work and, if so, if it was for the same or a different employer and at what comparative wage level. Administrative data has been used to analyze work retention and labor force participation for those taking short-term leave in Rhode Island, but unfortunately, based on conversations with researchers and state administrators, it is not clear that future access to these same data will be possible for other researchers.[19]

Health outcomes

Scholarship around health-related outcomes is not much more robust than for labor market outcomes. There are several data challenges that make identifying health outcomes challenging. There is generally a lack of overlap in surveys for health and labor force data that might identify the type of leave that employees take from work. Surveys with short reference periods—such as the one-week reference period for the Current Population Survey—can capture leave-taking in the reference week but will not capture health outcomes stemming from that leave. Surveys such as the National Maternal and Infant Health Survey do not exist for short-term disability leave and would be difficult to create because of the wide range of possible illnesses that would need to be captured. Only a few studies have attempted to assess how paid leave affects the health and recovery of those able to access it. What's more, many of those studies rely on small samples of specific groups with specific conditions rather than representative survey data.

Data needs and a path forward

Given the challenges described in the previous sections, identifying or collecting data on labor market outcomes and health outcomes around medical leave could fill a major gap in the literature around paid leave. For data in these areas, the path forward varies by the data source. For administrative data, researchers will need to gain access to state-level administrative data on temporary disability insurance before further research can be done. Just as was true for paid parental leave, if this state data could be linked with employment data from Unemployment Insurance earnings data or the U.S. Census Bureau's Longitudinal Employer-Household Dynamics program, then labor market outcomes and employment retention and wages could also be analyzed. This will be challenging given the limitations on access to individual-level data from state programs. While data will not be available immediately, it may be more fruitful to pursue relationships with states that are implementing programs now and to negotiate access to administrative data in exchange for research on the implementation and outcomes of the program once it is in place.

Beyond access to administrative data, identifying opportunities in survey data to capture both leave-taking and health and employment outcomes would be fruitful and possible in a shorter time frame. The American Time-Use Survey may be able to capture short-term health outcomes for individuals who have taken leave. It includes both a leave module and a well-being module, but unfortunately these modules have not overlapped in the years they have been implemented. The National Study of Caregiving (administered via the NHATS survey) may provide a useful sample for understanding some leave-taking and health outcomes. This survey interviews caregivers identified through the NHATS survey as providing care for individuals ages 65 and over, but it also captures the health status of the caregiver and any absence from work due to illness of the worker being surveyed. This may only capture short-term illness, as it does not record the duration of illness or the type of illness. Future waves of the DOL FMLA survey could specifically differentiate between the need for sick leave (short term) and medical leave (medium term) in order to better differentiate these types of leave.

Replication of the types of research that use small samples of specific conditions and the health outcomes related to leave-taking may be the most useful avenue for generating data in the short term. Without the same depth of research done for maternity leave, the literature in this area is sparse, and the survey data is not well-targeted to capture these leaves and resulting health outcomes. These small samples can be created more easily than alterations to representative surveys and can provide useful insights into the types of conditions where leave can provide health and employment benefits.

Paid caregiving leave

Key remaining questions

- What are the types of illnesses for which families need caregiving leave?
- Who needs care (spouses, children, adult parents)?
- How different is the level of demand for intermittent leave versus longer, uninterrupted stretches?
- What are the short- and long-term labor market outcomes of access to paid caregiving leave for both caregivers and (in some cases) the recipients of the care?
- How does caregiving affect caregivers' physical and mental health?
- How does caregiving affect the physical and mental health of the person receiving care?

Data used in current research

The outstanding questions related to paid leave for caregiving, similar to medical leave, require a more descriptive approach than for parental leave. The literature in this area is as diverse as the types of illness and care experiences of individuals providing care. And there is still a need to better understand what caregiving looks like and how best to address that need with leave. The diversity of families, the timing and duration of need, and the types of care that are needed all shape the caregiving role in ways that could result in different kinds of physical, mental health, or economic consequences. The programs providing access to paid caregiving leave also are relatively new, compared to temporary and short-term disability programs and pregnancy-related leave, making it impossible to judge the long-term effects of the program at this time. Yet detailed survey data on family caregiving has been increasing steadily, particularly for older adults. These surveys are fleshing out necessary details about the needs of caregivers.

Eldercare

The National Health and Aging Trend Study provides detailed information about the types of care, caregiving relationships, needs, and burdens of caregivers

and care recipients over the age of 65. Not all caregivers are caring for someone over that age, but more than half of adults between the ages of 85 and 89 need a caregiver, and about 76 percent older than 90 do.[20] The National Study of Caregiving, the companion to NHATS, creates networks of caregivers by identifying up to five individuals who provide care for an NHATS respondent. While NHATS only began in 2010 and cannot capture pre- or post-effects for California and New Jersey paid leave programs, it will be a powerful tool for understanding the effects of new paid leave programs that are being introduced in states that have not previously provided these benefits.

Data on the types of illnesses that caregivers provide care for are scattered across surveys, some large and some small, some nationally representative and others fielded by advocacy organizations to target a particular population. For nonelder care, data is more limited, as no NHATS equivalent is available for those caring for someone under the age of 65. There are some surveys on other types of illnesses, but these are more likely to be convenience samples sought out for their experience with caregiving. The National Alliance for Caregiving has fielded surveys looking at caregiving for rare health conditions,[21] though less than one-quarter were providing care for a short duration (2 years or less). For these caregivers, an uninterrupted stretch of leave may not be as beneficial as intermittent leave, and the extended length of care may result in lower workforce attachment among these caregivers. In the NAC survey, however, only 18 percent of caregivers reported giving up work or retiring over the past year. Survey data such as these provide a descriptive foundation for understanding the types of illnesses caregivers are providing care for and can capture some self-reported consequences.

Analysis about caregiving outside of parental leave using administrative data has been limited, particularly with regards to the effects of state paid leave programs. Existing survey data is still building descriptive statistics around the incidence of family caregiving and relationships between caregiving and labor force participation and health outcomes, but does not necessarily link the effects to access or take-up of paid leave programs. National survey data from the Health and Retirement Study and American Community Survey have been used to identify a population of likely caregivers and estimate effects of paid leave availability on leave-taking, employment, and labor force participation on this population.[22] Another study used the Health and Retirement Study to examine the impact of time spent assisting elderly parents on labor supply at midlife using a sample of women ages 55 to 67, but did not capture the use of paid leave.[23] The American Time Use Survey includes data on eldercare in the United States, including demo-

graphic information and detailed time-use data that helps fill in a picture of caregiving, though without covering impacts on long-term employment and wages.[24]

Labor market outcomes

Labor market outcomes have been analyzed for caregivers using survey data. The Survey of Income and Program Participation has been used to study caregiving using data from the 1986–1988 panels to analyze the relationship between women providing care to a disabled elderly parent and the effects on labor supply.[25] The National Longitudinal Survey of Mature Women was used to examine the relationship between employment and caring for an ill or disabled friend or relative over a 3-year period but, again, did not connect it to the availability or use of paid leave.[26] Surveys such as the Panel Study of Income Dynamics, which is longitudinal, could look at caregiving status and employment, but it does not capture leave-taking behaviors.

Administrative data could be useful for identifying individuals who are receiving leave for caregiving. If this data were connected to employment data, then researchers could also track employment outcomes such as job retention and wages. But with such a small subset of individuals receiving a paid leave benefit, it may be more important to understand those that need leave for caregiving but are not receiving any pay to provide it.

Health outcomes

Research on health outcomes for caregivers has largely targeted caregivers of older adults. There are several datasets—particularly the National Health and Aging Trend Study and National Study of Caregiving surveys—that capture the effects of eldercare on the health of the care recipient and caregiver, but the physical and mental effects for a caregiver of an older adult with dementia will be different from a younger spouse with cancer and will also be different from a person recovering from an accident or short-term illness. Answering questions about the effects of the physical and mental health outcomes for caregivers is challenging simply based on the diversity of experience that exists.

Some datasets reach caregivers caring for individuals who are not older adults. The Work, Family, Community Nexus survey, conducted by researchers Alison Earle from the Institute on Urban Health Research at Northeastern University and Jody Heymann from the Institute for Health and Social Policy at McGill University, uses a sample of employed U.S. adults ages 18 to 69 to study whether paid leave can mediate the relationship between caregiving and health.[27] For the California

paid caregiving leave program, surveys investigating the effect of paid family leave on leave taken to care for a chronically ill child—an underrepresented population in the research—use a targeted sample from children's hospitals. Some studies have compared groups of patients in California depending on whether leave was taken, and others look to results in California, where leave is available, compared to those of a state where paid leave is not available.[28]

Data needs and a path forward

The variety of surveys that include information collections about caregiving are illustrative of the growing interest in this area. Many surveys have added questions on caregiving over time as demand for knowledge in this area grew. There are datasets available that provide insights about paid caregiving leave that can be used to examine trajectories of caregiving and the burden of caregiving for different types of conditions.

As the U.S. population ages and many older adults remain in the workforce as they age, the need for caregiving will only increase. Estimates vary widely on the number of caregivers for older adults but the National Academy of Sciences estimates that there are at least 17.7 million caregivers of older adults in the United States.[29] This number will likely only grow and does not include caregivers who are taking care of sick children or adults under the age of 65.

Information on family caregiving for individuals under 65 years old is less well-documented than for eldercare. There is a lack of information on the care for sick children beyond the period of maternity or paternity leave and for younger spouses and family members. These incidents of caregiving may be rarer, but the trajectories and effects are not well-understood. Overall, analyses have been limited to short-term measures either by the survey design or by the number of years of survey data available.

There are several surveys now generating additional data on family caregiving for older adults, a population with an increasing need for caregiving. Other populations that may receive care due to illness or injury—for example, children who are past the age of maternity and paternity leave but are sick, or individuals who need treatment for cancer or postsurgical recovery—are poorly represented in the data. One approach to remedying this lack of non-eldercare related data would be to lobby to include additional questions about this type of caregiving in the main surveys conducted by the federal government such as SIPP, PSID, and the

ATUS leave module, where there are already questions on caregiving. This type of addition would be more feasible than expanding the age range for more detailed caregiving surveys such as NHATS or HRS but would still expand the universe of possible caregiving situations being described and could shed light on underrepresented caregiving experiences.

Administrative data around caregiving poses many of the same challenges to access as for parental and medical leave. But an additional challenge for caregiving leave is the small sample size of individuals receiving benefits for caregiving. In the first 10 years of California's program, only 175,198 claims were for caregiving, which is only about 10 percent of the total of 1,698,105 claims filed. In New Jersey, only one in five leave claims are for caregiving. While far fewer claims are filed for caregiving leave, the administrative data can be useful but are not nearly as rich in detail as survey data. To process the claims, data on the need for leave and the estimated duration must be collected from forms submitted by health professionals, but these data are not captured in the publicly available data.

The current political environment around data collection is difficult. The conclusion of the bipartisan Commission on Evidence-Based Policy Making, established by the U.S. Congress through the Evidence-Based Policymaking Commission Act of 2016, may set the stage for future momentum in the collection and use of data at the federal level, but it seems clear that this will take time.

The commission's final report provided an inspirational conclusion for the future of data and evidence in government:

> *The Commission envisions a future in which rigorous evidence is created efficiently, as a routine part of government operations, and used to construct effective public policy. Advances in technology and statistical methodology, coupled with a modern legal framework and a commitment to transparency, make it possible to do this while simultaneously providing stronger protections for the privacy and confidentiality of the people, businesses, and organizations from which the government collects information.*[30]

The goals of the commission would move government data collection and data sharing forward significantly if implemented, but the final report called for Congress and the president to ensure that the vision would become a reality. Whether that will happen is uncertain.

Demographics

Key remaining questions

A common question across all types of leave concerns the effects of demographics on outcomes for participants. Some of these more detailed demographic questions include:

- How do labor market effects such as job retention, employment status, and wages differ based on use of paid leave across racial and ethnic groups?
- How do care needs and labor market effects of caregiving leave vary by race, age, and other key demographic factors?
- How do the labor market and health outcomes for leave to recover from an illness or injury vary by race, age, and other key demographic factors?
- Do the impacts of policy design elements such as wage replacement rates, length of leave, work history, or job protection vary by race, age, and other key demographic factors?

Data used in current research

Inequities in access to government programs are not unusual. Nor are inequities in labor market and health outcomes. Inequities in the U.S. labor market generally and in the distribution of wealth mean that the burden of unpaid leave or job loss resulting from a need for leave may disproportionately affect nonwhite subgroups. Hispanic and African American families have a much lower median household income and considerably lower earnings that would make unpaid leave harder to manage.[31]

Many researchers are interested in the effect of paid leave programs on different subgroups, but data with sufficient sample sizes for subgroup analysis or detailed demographic data is limited. Some survey data exists on the experience of paid leave participants based on race and education level.[32] And some focus groups have targeted particular demographic groups to shed light on the qualitative

experience of paid family leave.[33] California has even done some market research to look at linguistic and cultural barriers to the use of paid leave benefits.[34] These smaller datasets do not allow for broader insights about utilization rates, effects, and variance among different populations.

In 2016, the National Academy of Science conducted a consensus study on family caregiving for older adults with a committee of 19 experts in the fields of caregiving, economics, and long-term services and support. The committee sought to develop a report with recommendations for public- and private-sector policies to support the capacity of family caregivers to perform critical caregiving tasks, to minimize the barriers that family caregivers encounter in trying to meet the needs of older adults, and to improve the health care and long-term services and supports provided to care recipients. The report summarized the state of the evidence in this area and highlighted some key shortcomings. The report found that:

> *Due to resource constraints, all the surveys that are relevant to family caregiving are limited in size, which in turn limits subgroup analyses. No current survey has sufficient power to assess the needs and experiences of older adults and their caregivers by all of the varied subgroups of interest, including those defined by race and ethnicity, rural residence, or sexual orientation.*[35]

While this only considered caregiving for older adults, it holds true for other components of paid leave as well.

There has recently been some additional progress made in studying racial and ethnic disparities in paid leave access and utilization. Health economists and medical and policy scholars Ann Bartel and Soohyun Kim at Columbia University, Jaehyun Nam at Pusan National University, Stanford's Maya Rossin-Slater, the University of Virginia's Christopher Ruhm, and Jane Waldfogel at Columbia recently completed an analysis of the American Time Use Survey leave module, the Current Population Survey's Annual Social and Economic Supplement, the National Study of the Changing Workforce, and the Survey of Income and Program Participation to find that, in particular, Hispanic workers have lower rates of paid leave access than white non-Hispanic survey participants.[36] This kind of work is a promising approach to tackling subgroup analysis using representative surveys.

Data needs and a path forward

Understanding the different needs of U.S. subpopulations and how they vary can have meaningful implications for the outcomes of the program. Without understanding which subpopulations are over- or underrepresented in take-up rates for paid leave programs, how barriers vary for these subpopulations, and the ways a program could be tailored to be more accessible, disparities can persist without recognition and programs cannot be improved.

Administrative data for paid leave does not provide detailed demographic data. States with existing programs do have data going back years—California for more than a decade—but the agencies administering these programs do not collect detailed demographic data in order to impose the minimum burden on applicants, while compiling enough data to run the program effectively. In this case, the needs for minimizing burden and maximizing privacy are at odds with the desire of researchers for rich data.

For states that have existing paid leave programs, characteristics such as gender, race and ethnicity, and age are not recorded in public data released on programs. These programs collect data on age using date of birth and on gender, though none ask about race and ethnicity. To understand program effects at the subgroup level, additional data linkages must be made or techniques such as imputation used to make finer levels of analysis possible.

While imputing race is not common in the existing academic literature on paid leave, methods for imputing race have been tested in other areas and could be brought to future paid leave research on the implications for subgroups. Race imputation based on surnames has had mixed results, with more success for some groups than others. The Rand Corporation developed a method to integrate surnames and geocodes for race/ethnic coding, which improved accuracy for African Americans and Asians, but not for Native American or multiracial individuals.[37]

Other researchers have been more successful identifying Hispanic individuals using surname-based imputation.[38] Still others use preferred language for receiving materials and residence location to impute race and ethnicity.[39] These techniques have not been validated for datasets of paid leave participants but could offer an alternative to increased burden on program participants tied to asking for this information to be reported. Testing these methodologies could offer useful tools for researchers who want to work with administrative data to understand the impacts of programs for different subgroups.

In addition to better understanding the way U.S. subpopulations interact with existing programs, building a foundation for tailoring programs in the future requires additional qualitative data on:

- The program users' knowledge of the program
- The program users' experiences in the program
- The impacts upon the program users' employment status
- The ways in which paid leave benefits helped program users economically, physically, and mentally

This type of qualitative data could be collected through interviews and focus groups focusing on including subgroups where existing data is not sufficient to analyze their experience of the program.

Firm-level effects

Key remaining questions

- How does paid leave impact employee turnover and firm productivity?
- How do these effects vary across firm size, industries, occupations, and local labor markets?
- How does medical and caregiving leave affect firm outcomes?
- How does access to paid leave, especially for low-earners or low-skill workers, impact firm outcomes?

Data used in current research

A few notable surveys, particularly the Department of Labor Family and Medical Leave Act survey, have gathered data on the impact of leave-taking on firms, whether paid or unpaid. A key question about the feasibility of paid leave remains the return on investment or potential negative effects on businesses, particularly small businesses, yet data about turnover rates and productivity are limited. Surveys that currently exist ask for the self-reported effects of paid leave on costs for the business, perceptions about abuse of the program, and about coordinating paid leave with other benefits offered by the employer.[40]

The DOL FMLA survey includes data on the self-reported effects of providing paid leave on firms, including costs associated with administering the program and how employers cover work when employees are on leave. This survey is probably the most comprehensive survey of effects on employers, with interviews from more than 1,800 worksites, though it does not specifically differentiate between unpaid and paid leave.

Similarly, there are other studies that use survey data from various employers to gauge attitudes toward paid leave and impacts of programs where they exist. These

surveys vary in size but capture some data on employers.[41] The Society for Human Resource Management and the Family and Work Institute currently field a large survey of 920 employers that includes data about what type of leave they offer but does not capture some of the firm-level outcomes. The survey captures the rationale for offering programs that are not mandated and self-reported obstacles to offering benefits. In 2016, Deloitte, a global consulting firm, conducted a survey of 1,000 employees to gauge the impacts of parental leave, and similarly, Pivotal Ventures, the executive office of Melinda Gates, commissioned Ernst & Young LLP, a professional service organization, to survey more than 1,500 human resource decisionmakers and more than 3,000 employees on the role of paid family and medical leave in workplaces and the impacts it has.[42]

Smaller samples of employers have also been used to study the effects of paid leave programs. In 2016, the scholars Bartel, Rossin-Slater, Ruhm, and Waldfogel used a survey of small and medium businesses in Rhode Island to study firm characteristics and productivity, employee life events and work flow, and employer-provided benefits. This survey also collected data from Massachusetts and Connecticut employers over the same time period to compare responses within similar states that do not have a paid leave benefit. Similarly, Sharon Lerner and Eileen Appelbaum at the Center for Economic and Policy Research conducted similar surveys in New Jersey based on 18 in-depth interviews with employers in a variety of industries.[43]

Data needs and a path forward

Considering the data currently available, the large samples available through DOL FMLA employer surveys or the Society for Human Resource Management and the Family and Work Institute survey seem to provide the most promising potential resource for robust data on employers. If questions about effects on outcomes for employers around cost, turnover, and leave-taking behaviors of employees could be introduced into questionnaires for future iterations of the survey, then they could reach a larger sample than fielding new samples of willing employers.

Beyond survey data, there are beginning to be attempts to tap into administrative data collected by employers rather than the state. One approach in this area was described at the convening of experts leading up to this report. Panorama, a Seattle-based think tank, hopes to make progress in collecting employment data directly from employer tracking systems rather than from surveys, and promote public reporting of data related to paid leave. While Panorama's current reach is

small, at about eight companies from different industries and of different sizes, the organization hopes to grow the sample size over time.[44]

This effort is promising in its potential to create data systems that could give researchers access to data on employment and leave-taking but a much larger undertaking would be necessary to compile robust data on firm effects comparable to the reach of the DOL FMLA survey. If this preliminary effort is promising, then this type of work could lead to a blueprint for approaching employers and building a larger dataset that would provide a more direct insight into firm behavior than self-reported surveys. But considering the metrics and interoperability of data systems across employers, it will be challenging to create a larger dataset.

Interactions with other federal and state government programs

Key remaining questions

- How does paid leave interact with existing federal programs such as Supplemental Security Income, Social Security Disability Insurance, Medicaid, Medicare, Temporary Assistance to Needy Families, the Supplemental Nutrition Assistance Program, or the Women, Infants, and Children program?
- How does paid medical and caregiving leave, where it's now available, shape long-term care needs?
- How would a new federal paid leave program interact with existing state programs?

Data used in current research

Any serious consideration of providing paid family and medical leave at the federal level raises questions about how such a program could be implemented. The literature on interactions with other programs is not as rich as on the effects of programs on leave-takers and care recipients. Examining these questions now would facilitate more effective conversations about the logistics of launching a large new federal program. Unpacking potential interactions between existing benefit programs and a paid leave program requires considering several major federal and state programs.

Some attempts have been made to study and document these effects. In their paper, Massachusetts Institute of Technology economist David Autor and his co-authors use data from the CPS Annual Social and Economic Supplement and short-term disability coverage rates from the U.S. Bureau of Labor Statistics to examine the relationship between private short-term disability insurance and long-term Social Security Disability Insurance.[45] The authors were unable to estimate the impact on SSDI based on their empirical approach, but their work offers a valuable springboard for future study. Studies of the interactions between

paid leave and other federal programs such as Temporary Assistance to Needy Families, the Supplemental Nutrition Assistance Program, and the Women, Infants, and Children program are limited. But both SIPP and CPS have been used to probe interactions between births and program utilization.[46] These types of studies could be built upon to investigate the interaction with paid leave by studying utilizations rates prior to and after the implementation of paid leave, especially in states where programs will begin providing benefits in the next few years.

Evidence around the interactions between family caregiving and long-term care needs is mixed and largely based off of small samples with limited generalizability. Having a family caregiver is associated with fewer and shorter hospital stays for older adults, according to surveys such as Women's Health and Aging Study and its accompanying Caregiving Survey.[47] A relatively small sample of 156 patient-caregiver pairs was used to find that caregiving is associated with delayed or otherwise problematic hospital discharges and readmissions.[48] But a sample from the Chicago Health and Aging Project found caregiving associated with increased hospitalization.[49] Then, there are the randomized controlled trials that have been conducted, which demonstrate that when older adults' caregivers receive sufficient support, hospital readmissions and expenditures for emergency room visits decline and nursing home placement is delayed.[50]

Each of these studies is representative of a smaller-scale study of effects of caregiving, largely not specific to paid leave, and its effects on medical care and hospitalization. While exploring these relationships is important to understanding potential implications for programs, the scale of the studies limit generalizability. Additionally, the evidence is not yet strong enough to demonstrate cost-savings or even whether promoting caregiving results in positive outcomes for the health care system, or to complete a cost/benefit analysis of caregiving for long-term services and supports.

Data needs and a path forward

To better understand the implications of paid family and medical leave on interactions between these large programs, additional research needs to be done that considers take-up rates and costs associated with the provision of paid leave. The Survey on Income and Program Participation is well-positioned to study trends in take-up rates among different programs but does not have a strong focus on leave-taking outside of maternity-related leave. Administrative data can be a better

source of understanding the effects of new programs on existing programs. This could be particularly useful in states that are still implementing paid leave programs, where a baseline could be set prior to the beginning of benefit distribution.

Unlike in survey data, underreporting of the use of programs or confusion about which program a person is using is not a challenge. Accessing administrative data that includes enrollment information about programs such as Temporary Assistance for Needy Families, Social Security Disability Insurance, or Supplemental Security Income will be a challenge but would provide useful insights into caseloads and potential interactions between paid leave and other benefit programs. Barriers to this type of linked administrative data are discussed in the following section.

Policy components for paid leave programs

Key remaining questions

- How do policy design elements such as wage replacement rates, duration of leave, and job protection impact health effects and labor market outcomes for leave-takers?
- How do policy design elements impact health effects for children and care recipients?
- Do the effects of policy design elements such as wage replacement rates, length of leave, work history, or job protection vary by race, age, and other key demographic factors?

Data used in current research

There have been some studies of how paid leave policy elements—for example, the inclusion of statutory job protection so that leave-takers cannot be fired for taking leave—affect labor market outcomes. Additional examples include how the level of wage replacement or the portion of a person's salary provided as a benefit affects take-up rates for the benefit or how the maximum length of leave available affects take-up rates, job retention, and health outcomes. Some studies offer promising approaches for replication in other contexts and for further examination.

The inclusion of job protection so that workers who take leave cannot be fired for taking unpaid leave they are eligible for is a provision that is included in the federal Family and Medical Leave Act and in some state programs but not others. Understanding the impact of whether job protection is included is an important component of designing a policy. One study of the effect of job protection used data from the publicly available U.S. Census Bureau's Longitudinal Employer-Household Dynamics database, which includes employment data and data on industry dynamics and individual employment trajectories, to compare female employment within

firms in California to those outside of California to identify effects of paid leave with and without job protection on female labor market outcomes.[51]

In 2017, Sara Bana and Kelly Bedard at the University of California, Santa Barbara and Stanford's Maya Rossin-Slater used 10 years of linked administrative data from California to estimate the effects of the level of weekly benefits for women and their labor market outcomes, finding no evidence that a higher weekly benefit amount increases the length of leave taken or leads to adverse future labor market outcomes for mothers.[52] A U.S Government Accountability Office study cited research that indicated that job protection reduced the amount of time women spent out of the labor force.[53] The variation that exists in states and will continue to grow as additional states begin providing benefits of different generosities for different amounts of time to different groups of people allows for tests of the impacts of these differences on important metrics such as take-up rates, job retention or workforce participation, and health outcomes.

Design elements such as those discussed above may have important implications for the take-up of paid leave benefits, but program awareness is another key element driving uptake. Little is known about how to best ensure program awareness, and states with existing programs generally have not had the resources to test different approaches or to do sustained outreach. In this area, data on eligible individuals compared to individuals actually taking leave is the first step to identifying unmet needs where program awareness or other barriers exist. Then, testing outreach campaigns, anything from small so-called A/B testing of materials provided to new mothers, to large advertising campaigns would provide important information to other states trying to tackle similar program awareness challenges.

Some survey data exists that has targeted program awareness. Following the implementation of Rhode Island's Temporary Caregiver Insurance program, a survey was conducted to gauge program awareness among workers who were eligible for the benefit and workers who were not.[54] A similar survey was conducted in New Jersey to gauge public awareness of the benefit, finding awareness low, particularly among nonwhite adults, young adults, retired adults, and adults earning less than $50,000 per year.[55] A survey in California even targeted awareness among parents of chronically ill children, a likely underrepresented group in leave-taking given the low take-up rate of nonbonding leave.[56] Additional survey data need to be collected to better understand program awareness, particularly among groups that data like those in the DOL FMLA survey indicate have a need for leave but are not appearing in the utilization data for state programs.

Data needs and a path forward

These types of studies of program structure and benefit levels are rare but can be instrumental in policy conversations about the development of new programs for states considering paid family and medical leave legislation. They also are essential for deliberation about a federal paid family and medical leave program. Design questions will become increasingly critical as evidence for the need for paid leave becomes increasingly clear and a consensus for providing leave through a national program grows. Variation between states and within states where cities or counties are building on state programs provide exciting possibilities for examining how the structure and details of a program affect participation and outcomes.

Take-up rates are a major issue with regard to paid family and medical leave. While take-up rates among women for bonding after the birth of a child are much higher than for other types of leave, understanding who takes up the program is less clear. Take-up rates are much lower for fathers, adoptive parents, caregivers for other family members, and those who need leave to recover from a serious injury or medical condition. And there is still a lack of clarity about who is likely to take up the program, who is not, and why.

Comparing take-up rates in states when program components are changed—for example, when a benefit rate is increased or the length of leave is increased—provides a useful opportunity to study the effect of policy design on take-up rates. Comparing take-up rates in states with varying policy designs also can be useful, but to better understand take-up rates and target outreach to improve take-up rates, detailed demographic data about the characteristics of program participants and eligible individuals who opt not to participate is necessary.

State administrative data, however, does not capture detailed demographic information when an individual applies for benefits and also does not capture information about eligible individuals who do not apply. Using survey data to understand eligibility for benefits for individuals who have recently had a baby is the easiest way to understand the universe of possible beneficiaries and with detailed demographic information about program participants, could be used to understand what characteristics drive take-up of the program.

Implementation and policy design around paid medical leave for a personal illness pose unique challenges, and there are not currently good data available to help better understand the policy design decisions that goes into this type of leave. For

the birth of a child or an adoption, there is a clear and discrete event that is tied to the generation of a birth certificate or paperwork for verification purposes. For medical claims, adjudicating the severity and appropriate length of the benefit would be much more complicated.

States with existing temporary disability insurance programs have varying adjudication processes in place, and studies that compare the costs and benefits of each type of system could guide the development of a national program. In California, for example, medical certification is provided directly to the state from a licensed medical professional. Practitioners must provide the state with a diagnosis and an International Classification of Diseases, or ICD code—a system that is used to track and understand the clinical needs of patients. Medical professionals who submit documentation to the state also must provide an anticipated date when the individual is likely to be able to return to work.[57]

In Rhode Island, the process is similar but the health care industry's Official Disability Guidelines are used to determine the duration of leave. And in New Jersey, a health care provider must certify the date, if known, on which the serious health condition commenced and the probable duration, though the ICD and ODG codes are not required. Understanding if these systems result in different prescribed lengths of leave and then looking at employment outcomes could shed light on how policy designs affect labor force attachment.

First, access to administrative data where these codes are captured would need to be achieved. For the existing programs in California, New Jersey, and Rhode Island, data on ICD and ODG codes are not captured in the publicly available data on the programs, though they would be necessary for implementing such a program and so must be captured in the administrative data used by the state programs. Gaining access to this data at an individual level would allow for a better understanding of how policy design decisions affect outcomes for medical leave.

Barriers to data collection and access to data

Throughout this report, there have been references to barriers to progress on outstanding questions that stem from the lack of data currently available. These barriers take several forms: those created by policies, those that are the result of technological shortcomings, and those caused by a lack of data.

As a precursor to accessing data, there must be knowledge of the data that exists. Currently, despite the variety of surveys fielded from different sources that cover a range of relevant topics, there is not a directory to examine what variables have already been collected. There is a host of data available, but knowing it exists and how to access it can pose the first major barrier to research by taking valuable time to find out what exists before it can be used to answer new questions.

The table in the toolkit associated with this report is a first step toward creating a directory of data resources, but it is not exhaustive. Once surveys have been identified, researchers must still gain access to data. Some data are available in public use files but are limited for privacy and security reasons. Getting individual-level data often requires a lengthy application process, negotiation of a data sharing agreement, approval from an Institutional Review Board—an ethics organization for approving research—and potentially the ability to access a secure facility such as the U.S. Census Bureau's Research Data Center. Steps that ensure privacy and security of the data are essential, but it should be easier to understand what steps need to be taken.

For state administrative data, existing programs publish aggregate data about their programs online and through annual reports. This gives access to aggregate utilization rates, breakdowns by types of leave, parental leave, and length of leave. California even has a useful data portal to look at and download monthly aggregate program data on paid leave.[58] Rhode Island makes monthly summary reports available publicly on its temporary disability insurance site.[59] And New Jersey provides data in annual reports available on its Division of Temporary Disability and Family Leave Insurance site.[60] This aggregate data is useful in tracking utilization rates. But without individual-level data, researchers are unable to test for patterns

in use based on other factors such as demographic characteristics or firm type, or to look at outcomes over time.

Accessing individual-level data seems to be nearly impossible. For existing administrative data, attempts to access the data have been limited. Representatives from neither Rhode Island nor New Jersey could identify any instances of successfully completing data sharing agreements with outside research institutions. Rhode Island has released administrative data for a report on short-term disability and return to work.[61] Yet the process for that release is no longer viable, according to state sources. Rhode Island also had worked with the University of Rhode Island on a survey about awareness and access to the state's Temporary Caregiver Insurance program after it was enacted, but no administrative data was shared for the purposes of that research.[62]

Even California has had limited success working with academic research partners. The scholars Bana, Bedard, and Rossin-Slater used 10 years of linked administrative data from California to estimate the impacts of benefits,[63] but the policy of the state is that individual-level data cannot be released because of confidentiality standards set by the department and their Information Security Office. This means future use of these data may not be possible.

Moreover, even if in the future, procedures were put in place to allow for access to data for research purposes, another barrier to access would be technical. In California, Rhode Island, and New Jersey the systems for paid leave are built at least in part on the Common Business-Oriented Language, or COBOL, a programing language designed in the 1950s and 1960s. The challenges of using this system are two-fold. First, it is a legacy system for which engineers and programmers are few and far between, making them expensive and leaving few resources for nonessential tasks. Second, the system is difficult to alter. The program in New Jersey has begun a modernization of their system because the current model does not allow for even basic changes to the benefit levels or eligibility criteria, but upgrades take time and not every state will allocate resources to this endeavor. Hopefully, these technical challenges will be removed as new systems are built that are more flexible, have detailed data inventories, and provide the ability to generate reports for research purposes.

Important data are currently locked up in systems that are difficult to use and the bar-

Progress on administrative data

riers to achieving a data sharing agreement to access such data are significant. As new states pass paid family and medical leave laws, lobbying state legislatures to include funds for and legislative language about data infrastructure, security, and usage for program integrity and academic research could lower some of these barriers. New programs have the opportunity to avoid some of the pitfalls, especially with regard to information technology barriers with which states with existing programs struggle.

A useful addition to our toolkit would be a scaffolding for states that incorporates the type of language and system structures that have allowed for easier access to data for research purposes in other contexts. What type of language have states used in other programs where researchers can more easily access data? Are there ways states should think about contracting for IT systems that incorporates better data hygiene and data mapping? What would states with existing programs like to change about their IT systems, or are there best practices that could be shared with other states to maximize efficiencies in new systems?

In the meantime, a promising pathway to increase access to and use of existing administrative data is to create a "blueprint" for researchers similar to the one described by U.S. Department of Labor economists Christopher McLaren and Elliot Schreur and envisioned by the toolkit associated with this report to outline the process for acquiring data from specific state agencies.[64] Agencies that collect data on paid leave do not generally track employment and health outcomes, so data would have to be linked across multiple agencies in order to look at some of the outcomes of interest, requiring additional agreements and negotiations. While linking data owned by different agencies presents more of a challenge than for data owned by a single agency, such work makes it possible to create a much richer dataset for analysis of these programs.

The most promising potential for answering outstanding research questions is through building data linkages that connect paid family leave data to other administrative data on employment and health. To do so is a long, time-consuming process. Time is needed to build relationships and get buy-in from multiple agencies,

to ensure the data is in the necessary condition for creating linkages, and for the actual linking of the data.

Yet a telling example of this approach in action comes courtesy of Washington state and was described at the Washington Center for Equitable Growth convening in 2018 on paid leave. In partnership with researchers at the University of Washington, the state of Washington's Department of Social and Health Services Research and Data Analysis team developed the Washington Merged Longitudinal Administrative Database. WMLAD was created to examine the effects of the Seattle $15 minimum wage ordinance. While use of WMLAD is restricted to the University of Washington research team's work on the minimum wage, this or similar data could also potentially be used to examine the effects of the new state paid leave program and other state or local policies. WMLAD links unemployment insurance data and state administrative voter, licensing, social service, income transfer, and vital statistics records to create a dataset with information on employment and earnings data, along with information on age, sex, race and ethnicity, public assistance receipt, household membership, and demographics for most residents of Washington.[65]

Creating this dataset has been years in the making. It required building a strong, reciprocal relationship between the University of Washington researchers and the state's Research and Data Analysis staff. The RDA staff members were experienced at merging their internal data with Unemployment Insurance records. The University of Washington team helped to secure confidential linkable data from other agencies and to work with the RDA team on techniques for matching households. To get to this point, data sharing agreements to grant researchers access to the administrative data and state Institutional Review Board approval were necessary.

It took nearly 4 years into the project before the data were available to the University of Washington team. While its use is restricted right now, it is this kind of data infrastructure that would allow researchers to potentially answer questions about paid leave and the effects of paid leave on other programs, employment and earnings, and health outcomes in Washington state.

Washington state had an advantage in the existence of the RDA and the technical expertise that allowed for data linkages to be made. Some states will not have teams dedicated to data infrastructure and maintenance, and creating linkages such as those in the WMLAD database will be more difficult. Progress is measured in years, not months, and merging public records in this way necessarily requires state-of-the-art data security. But this type of data infrastructure could

make answering some of the more difficult questions about the effects of a policy such as paid family and medical leave possible.

A key take-away that Heather Hill, one of the researchers on the WMLAD team, emphasized was that relationships with state agencies need to be reciprocal. Researchers should try to find a way for their work or expertise to be useful to the state agency rather than simply requesting data access. This approach can help build stronger relationships and improve the likelihood that access will be granted.

The path forward

This report has covered many challenges and gaps that currently exist in the data around paid leave. There are plenty of useful datasets that researchers have used to answer important questions about paid leave, and continuing to use those datasets in creative ways will allow for future research to progress but there is more that can be done. There are several key actions that could be taken to ensure the development of better data on paid family and medical leave.

Researchers can:

- Advocate with administrators in states with existing programs to create processes that allow for use of administrative data in analyzing paid leave programs. While privacy should always be a concern, there are ways to protect privacy and still allow for research to better understand the impacts of these programs.

- Build on access to administrative data through data linkages with health and employment data to begin analyzing the long-term effects of these programs.

- Advocate with states just rolling out paid leave programs to incorporate a research agenda on the success and effects of their programs to ensure researchers gain access to new administrative data sources early in the process and that technological barriers can be overcome during the developmental stages of the program.

- Advocate for additional waves of the DOL FMLA survey to capture the unmet needs for leave, particularly among those needing to recover from an illness or injury or to care for a family member other than a new infant.

- Collect additional survey data to better understand program awareness, particularly among groups that data in the DOL FMLA survey indicate have a need for leave but are not appearing in the utilization data for state programs.

- Expand our toolkit to include guides for researchers interested in accessing administrative data. This guide could include:

  - An expansion of the inventory in this toolkit to create an easily accessible directory of available data for researchers to use in designing studies of paid family and medical leave
  - A step-by-step process for requesting data from states, particularly including contact information for the person or office responsible for executing data sharing agreements
  - A sample Memorandum of Understanding or Data Use Agreement that had successfully been used to access administrative data
  - Resources states could use to clean their data and prepare it for sharing
  - Model legislative or regulatory language that states could use to ensure proper and secure sharing of data in new programs as they are implemented so that researchers could advocate for better access going forward
  - Test and validate techniques such as race and ethnicity imputation with paid leave administrative data.
  - Advocate for the inclusion of specific questions about paid leave in surveys such as the Survey on Income and Program Participation and additional waves of the American Time-Use Survey's leave module.

Funders can:

- Ensure researchers pursuing data sharing agreements and data linkages across agencies are able to obtain long-term funding. Negotiating these agreements and accessing the data will take time—much longer than a year—and without sustained funding opportunities, it is unlikely that they will find success.
- Consider funding questions or modules for large representative surveys such as the Panel Study of Income Dynamics.
- Develop contacts in state legislatures and agencies to help advocate for proactive planning around data sharing in new programs.

Policymakers can:

- Ensure state and federal agencies have the infrastructure in place to ensure privacy while allowing for data sharing for research purposes.
- Remove legislative barriers to creating data sharing agreements.
- Support and fund additional waves of important surveys that collect data on paid family and medical leave and advocate for inclusion of questions on paid family and medical leave.

The time has come to build on the strong foundational research in the area of paid leave across the United States. Exciting work in data linkages, building relation-

Conclusion

ships with private employers willing to share data on their workforce and the implementation of paid leave policies, and detailed investigations of the effects of population subgroups who use paid leave are being done. This work will continue to build on the evidence for this policy intervention but data needs represent a major challenge to furthering a research agenda.

Administrative data from state programs could provide a wealth of knowledge. Developing better systems at the state level and allowing researchers to access data should be a priority. By linking administrative data on paid leave with other state administrative data, it would be possible to track employment outcomes, health outcomes, and use of other social programs.

There is also a need to focus on collecting more detailed data on medical and caregiving leave. Available survey data does not capture sufficient detail to understand the types of conditions during which individuals need leave and the variation in outcomes that results from these varying needs. Survey data need to focus on collecting more data on medical and caregiving leave to build on the foundation of research that currently exists and catch up with the research on parental leave around health and employment effects. Addressing this gap with new data would facilitate better understanding of the needs of caregivers and the ways that paid leave programs can best address those needs to promote better outcomes.

The need for paid family and medical leave is clear. As more states consider or implement programs to provide this benefit and as a federal program is considered, the research powered by the types of data discussed in the report will help support better policy decisions, will help policymakers better understand the impacts of their design decisions, and will support future improvements to existing programs, ultimately improving the health and employment outcomes of countless families.

Glossary of data sets

Listed in alphabetical order by acronym or the full name of the database:

ACS—American Community Survey (U.S. Census Bureau)

ATUS—American Time-Use Survey (U.S. Bureau of Labor Statistics)

CPS—Current Population Survey (U.S. Census Bureau)

DOL FMLA—Department of Labor Family and Medical Leave Act Worksite and Employee Survey (U.S. Department of Labor)

HRS—Health and Retirement Survey (University of Michigan)

LEHD—Longitudinal Employer-Household Dynamics (U.S. Census Bureau)

MarketScan® Health and Productivity Management (IBM MarketScan Research Databases)

MarketScan® Commercial Claims and Encounters (IBM MarketScan Research Databases)

National Alliance for Caregiving survey (National Alliance for Caregiving)

National Longitudinal Survey of Youth (U.S. Bureau of Labor Statistics)

NSOC—National Study of Caregiving (Johns Hopkins University Bloomberg School of Public Health)

National Study of the Changing Workforce (Society for Human Resource Management)

NCS—National Compensation Survey (U.S. Bureau of Labor Statistics)

NHATS—National Health and Aging Trends Study (Johns Hopkins University Bloomberg School of Public Health)

NSAF—National Survey of America's Families (The Urban Institute's Assessing the New Federalism research project)

PSID—Panel Study on Income Dynamics (University of Michigan's Institute for Social Research)

SSA-DER—Social Security Administration Detail Earnings Records (U.S. Social Security Administration)

SIPP—Survey of Income and Program Participation (U.S. Census Bureau)

Social Security Disability Insurance administrative data (Social Security Administration)

Supplemental Security Income administrative data (Social Security Administration)

Supplemental Nutrition Assistance Program administrative data (U.S. Department of Agriculture)

Temporary Assistance for Needy Families administrative data (U.S. Department of Health and Human Services)

Viewpoints on Paid Family and Medical Leave (Ernst & Young LLP commissioned by Pivotal Ventures)

Vital Statistics (The Centers for Disease Control and Prevention)

WMLAD—Washington Merged Longitudinal Administrative Database (Washington state's Department of Social and Health Services Research and Data Analysis)

Women's Health and Aging Study (John Hopkins University's Center on Aging and Health)

Women, Infants, and Children program administrative data (U.S. Department of Agriculture)

Work, Family, Community Nexus survey (Institute on Urban Health Research at Northeastern University and Institute for Health and Social Policy at McGill University)

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Acknowledgements

The author would like to thank Elisabeth Jacobs and Alix Gould-Werth for all their support in the development and execution of this report; Ed Paisley and the Washington Center for Equitable Growth Editorial team for their excellent editorial and design support; Jill Gutierrez, Heather Hill, Chris McClaren, Amy O'Hara, Ray Pepin, Kimble Snyder, Jane Waldfogel, and Jennifer Wolff for sharing their experience and insights; and all the participants in the Advancing the Evidence on Paid Family + Medical Leave event on October 24, 2018.

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