

Children with Health Issues

Mark A. Schuster, Paul J. Chung, and Katherine D. Vestal

Summary

All children, even the healthiest, have preventive and acute health care needs. Moreover, a growing number of children are chronically ill, with preventive, acute, and ongoing care needs that may be much more demanding than those for healthy children.

Because children are unable to care for themselves, their parents are expected to provide a range of health care services without which the current health care system for children would not function. Under this “shadow health care system,” parents or parent surrogates often need to be with the child, a requirement that can create difficulties for working parents, particularly for those whose children are chronically ill. How federal, state, and employer policies and practices mesh with the child health care needs of families is therefore a central issue in any discussion about work and family balance.

In this article Mark Schuster, Paul Chung, and Katherine Vestal describe the health care needs of children; the essential health care responsibilities of parents; the perspective of employers; and the existing network of federal, state, and local family leave benefits that employed parents can access. They also identify current gaps in policies that leave unmet the needs of both parents and their employers.

The authors suggest the outlines of a national family leave policy that would protect the interests of parents and employers. In essence, such a policy would build on the federal Family and Medical Leave Act, which gives some workers time off with no advance notice required and no loss of job or health insurance. But it would also include elements of California’s Paid Family Leave Insurance, which expands coverage to more workers and provides partial pay during leave. Employers could be given some financial protections as well as protections against employee fraud and abuse. Such a policy, the authors conclude, would help to provide security to parents, minimize effects on employers, raise societal expectations for family-friendly work environments, and help maintain the parental shadow system of care on which health care professionals depend.

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For the past two decades, family leave has been viewed in the United States as one of the core tools in helping parents address their children's health care needs. The federal Family and Medical Leave Act (FMLA) of 1993 provides unpaid family leave primarily to long-term employees working more than half time for public agencies or large private employers. Several states and the federal government have implemented or are considering implementing expansions that provide pay during leave, reach more employees, or both. Employers, meanwhile, are increasingly introducing greater scheduling flexibility, access to child care, and paid leave. For these governmental and employer policies to be most effective, they must take into account children's preventive, acute, and chronic health care needs, the associated health care responsibilities of parents, and the costs for employers.

Even the healthiest children have substantial health care needs.¹ All children are expected to receive routine preventive care that addresses not only the screening and prevention of disease but also the promotion of healthy development. Virtually all children also need acute intermittent care (at home, in outpatient settings, or in hospitals), often multiple times a year, for illnesses ranging from minor to serious. Moreover, a large and growing subset of children is chronically ill, with ongoing preventive, acute, and chronic health care needs that may be dramatically greater than those of healthy children.²

A distinct feature of health care for children is that parents are expected to perform nearly all of the support roles that make direct services by health care professionals possible. Moreover, parents themselves must provide (free of charge) direct health care services,

many of which were once considered to be the responsibility of health care professionals. In general, the number, frequency, and complexity of these parent-provided services increase with the severity of the illness, and health care system reforms that encourage home care over hospital care typically do so with the full expectation that parent responsibilities will increase. It is not an exaggeration to view parents as the linchpin of a shadow health care system without which the formal child health care system would be unable to function. To provide this shadow care, parents or parent surrogates must be present with the child.

Employed parents currently rely on a patchwork system of employment policies and family leave benefits (as well as the informal accommodations of employers and coworkers) to maintain this shadow system of care. Employers, meanwhile, have interests in ensuring that provision of this shadow care does not unduly affect workplace productivity. How federal, state, and employer policies and practices mesh with the child health care needs of families is therefore a central issue in the ongoing national discussion about work and family balance. In this article, we describe the health care needs of children, the essential health care responsibilities of parents, the perspective of employers, and the existing network of benefits that employed parents can access. We also identify gaps in these benefits that may be particularly salient for the types and patterns of care responsibilities that parents shoulder.

What Are Children's Health Care Needs?

Although children are, on average, healthier than adults, their health care needs, even in the best of circumstances, are considerable.³ Like adults, children require care in three

Figure 1. Domains of Pediatric Care and Examples of Care in Each Domain

<p>Routine preventive</p> <ul style="list-style-type: none"> • Immunizations • Developmental screening • Disease screening • Anticipatory guidance • Preventive dental care 	<p>Intermittent acute</p> <ul style="list-style-type: none"> • Acute office visits • Emergency department visits • Hospitalizations • Home care and services 	<p>Ongoing chronic*</p> <ul style="list-style-type: none"> • Multispecialty physician services • Specialty nursing services • Speech, physical, and occupational therapy services • Home care and services • Mental, developmental, and behavioral services
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Source: Authors.

* Chronically ill children require enhanced routine preventive and intermittent acute care, as well as ongoing chronic care.

basic domains: routine preventive care to promote health, prevent disease, and reduce unhealthy behaviors; intermittent care to diagnose and treat acute illnesses ranging from minor to life-threatening; and ongoing care to manage chronic conditions that persist over months or years. Figure 1 gives examples of the health care services that fall in each of these three categories.

Until a few decades ago, these three types of care were weighted toward preventive and acute care; chronic care needs affected relatively few children. Therefore, parents generally needed only occasional brief absences from their work on behalf of their children. Moreover, traditional gender roles, with mothers typically staying home with the children, ensured that such absences for employed parents (usually fathers) would be few and far between.⁴

In recent decades, however, chronic care needs have substantially expanded with no diminution of preventive and acute care needs. Illnesses that previously killed children (such as severe prematurity, cancer, and genetic diseases) have become, in many instances, nonfatal conditions with long-lasting effects that require extensive,

sometimes lifelong, management. Meanwhile, the number of childhood preventive services now recommended has greatly increased, leading to even higher frequency and intensity of routine care.⁵ For the most part, workplaces have not developed effective strategies to adapt to these changing demands, and gender role shifts have guaranteed that the need for absences related to child health and health care, once uncommon, are now a ubiquitous part of workplace life.

Preventive Care

All children are expected to receive a large and ever-growing amount of routine preventive care, including immunizations, developmental surveillance and disease screening, anticipatory guidance (providing education and advice to promote health and prevent disease), and dental care. Currently, the American Academy of Pediatrics and Bright Futures (a national child health promotion and disease prevention initiative that is explicitly referenced in the 2010 Patient Protection and Affordable Health Care Act⁶) jointly specify a minimum of seven visits in a child's first year, six more in the next three years, and a total of twenty-six before the age of eighteen, a frequency far greater than recommended for most adults.⁷

The underlying causes of the relationship between socioeconomic status and child health are not yet well understood, but the discrepancy in health status between social classes has persisted over time.

Immunizations are a public health priority. They protect recipients and the public at large, through “herd immunity,” against serious diseases. The number of diseases for which immunizations are recommended continues to grow, and most immunizations require multiple doses at multiple visits.

Developmental and disease screenings are also staples of preventive care. Developmental screening detects delays and problems in physical maturation; speech and language acquisition; gross and fine motor skills; and behavioral, social, and emotional growth. Disease screening consists of a general history, a physical exam, and specific tests. The history and physical exam elicit parent and child concerns and attempt to find incidental signs or patterns of early or hidden illness. Specific tests detect congenital diseases, vision and hearing deficits, anemia, lead exposure, obesity, hypertension, and sexually transmitted infections. Early detection and treatment of delays and diseases in these areas have been associated with short- and long-term health, educational, and economic benefits.⁸

Anticipatory guidance is considered by many pediatric clinicians to be the cornerstone of

the childhood preventive care experience. It consists of education given to parents and children (especially adolescents) regarding the prevention of diseases and the promotion of healthy growth and development.

Recommended anticipatory guidance topics are far too numerous to detail but include advice on topics such as breast feeding and sleeping position for infants, discipline and injury prevention for toddlers, school performance and nutrition for elementary-school-age children, and substance use and sexual health for adolescents.⁹

Finally, regular dental care has become increasingly recognized as a major determinant of health. Tooth decay and periodontal disease are associated with complications caused by infection and chronic inflammation.¹⁰ Some health care professionals now recommend that children have their first routine dental visit as early as age one, with routine follow-ups recommended as frequently as every six months.¹¹

Care of Intermittent Acute and Ongoing Chronic Illnesses

Children may experience a great range of illnesses, from mild to severe, and from common to rare. These conditions may last for a day or two or for a child’s whole life.¹² Most are intermittent acute illnesses such as infectious diseases (common colds, pneumonias) and injuries (car accidents, falls), but a substantial and growing percentage are chronic illnesses. The most common chronic childhood illnesses include allergies, asthma, attention-deficit/hyperactivity disorder (ADHD), and emotional problems. Other well-known and relatively common chronic illnesses include cancers, developmental and behavioral disabilities (such as autism), congenital abnormalities, cerebral palsy, complications of prematurity, cystic fibrosis, and diabetes.

The prevalence of many of these conditions (both acute and chronic) has been shown to vary by socioeconomic status.¹³ On average, children with poorer parents are less healthy than children whose parents are financially better off. For instance, more than twice as many poor children as nonpoor children are reported by their mothers to be in less than “very good” health, a gap that increases as children age.¹⁴ The underlying causes of the relationship between socioeconomic status and child health are not yet well understood, but the discrepancy in health status between social classes has persisted over time.¹⁵

Intermittent Acute Care. In addition to receiving routine preventive care, almost all children will have one or more illness episodes serious enough to require an outpatient or emergency ward visit, hospitalization, or care at home. It is difficult to disentangle preventive from acute office visits in administrative data sets. Nevertheless, about three of four children under age eighteen have at least one office visit in a given year, with an average rate of about four visits a year; that rate would suggest an average frequency far in excess of the recommended routine visit schedule. Moreover, about one in eight children in a given year has at least one emergency ward visit, and about one in thirty is hospitalized at least once. For children described by their parents as being in only fair or poor health, the numbers are dramatically higher, with five of six having at least one office visit (at an average rate of nine visits a year), one in four having at least one emergency room visit, and one in seven being hospitalized at least once.¹⁶

On top of these acute health care encounters are days in which children suffer minor illnesses that may not require care by medical professionals but still prevent them from attending day care or school or that otherwise

require parental presence at home. About 70 percent of children in elementary school miss some school each year because of illness, with 15 percent missing more than one week.¹⁷ Thus, it is entirely likely that intermittent acute care necessitates multiple days of health care services (by providers or parents) each year even for otherwise healthy children, and potentially weeks of services for children who are seriously ill.

Ongoing Chronic Care. Finally, about 15 percent of children are considered children with special health care needs—children “who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”¹⁸ For instance, children with conditions such as ADHD, asthma, autism, cancer, cerebral palsy, cystic fibrosis, depression, diabetes, and sickle cell anemia generally fall into this category. These children require ongoing care, including frequent monitoring, interventions aimed at preventing or managing complications of the illness, and often high-intensity acute care for severe episodes of illness. They account for a vastly disproportionate number of hospital days, health care encounters, and school absences.¹⁹ Although fewer children are chronically ill than adults overall, the number of children with special health care needs appears to be growing. Moreover, these children are at high risk for permanent physical and developmental impairments that may create large societal costs lasting an entire lifetime. Intervening in an appropriate and timely fashion is critical for their health maintenance and long-term prognosis.

Intervening, however, is often an enormously complex undertaking. Chronically ill children

typically do not have a single health care provider who delivers all necessary services. Instead, management of childhood chronic illnesses is generally a multisystem, multiprovider effort requiring intensive coordination. Most chronically ill children require specialty physician services, and many require the input of multiple physician specialists, often in separate venues. In addition, about 20 percent of all children in a given year receive health care from nonphysician providers, with much of this care focused on the chronically ill. These services include specialty nursing visits; speech, physical, and occupational therapy; home health services for intensive or complex therapies as a way to avoid long-term or even permanent hospitalizations; and mental, developmental, and behavioral health services. About a quarter of children with special health care needs use speech, physical, or occupational therapy each year, and about one in twenty uses home health services each year.²⁰ Typically, these services require separate providers who do not routinely communicate with each other, forcing constant and active supervision.

Variations in Patterns of Care Needs

There is an additional factor complicating children's health care needs—the large and unpredictable variations in need that occur not only among different children but also for the same child over time. As noted, a single health care episode can last a day, a week, a month, or a lifetime. A history of shorter durations of illness for an individual child does not eliminate the possibility of a serious or even catastrophic event in the future. Conversely, the fact that a child experiences long-term health care needs does not mean that additional short-term needs are somehow diminished. In fact, chronically ill children exhibit, on average, greater use of preventive and acute care services than other

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children.²¹ Therefore, as the complexity of illness increases, so does the variation in the durations of health care episodes.

The same can be said with respect to frequency. Children with special health care needs typically use health care services more frequently than children without such needs. However, children can become chronically ill at any time, and many may recover or improve substantially over time. Childhood cancers, for instance, can appear at any age (depending on the type of cancer) and, once they present, can immediately increase health care needs for long periods of time. But those health care needs are not static. Instead, they fluctuate dramatically depending on factors that are largely outside the family's control—available treatment options, initial response to treatment, acute or chronic complications resulting from either the cancer or its treatment, and spread or recurrence of the cancer. These fluctuations can occur both rapidly and suddenly—children with special health care needs, for instance, are more than three times as likely as other children to have an acute illness episode requiring admission to an intensive care unit.²² That does not mean,

however, that all children with special health care needs will require such services, or that all other children will not.

What it does mean is that health care needs vary enormously among children, especially among those with special health care needs, and that this variation is often unpredictable. Thus, an examination of children's health care needs suggests that policies designed to help parents care for their children will be most effective if they take into account this most basic fact of life and health.

Parents: The Central Hub of the Child Health Care System

Children occupy a special position with respect to health care. Few other populations are as dependent on others for their health care. Because of this dependence, a societal obligation is attached to the parents (or parent substitutes). Whether the care is preventive, acute, or chronic, parents are simply expected to be there, and many of the processes of care have been arranged based on an assumption of parental presence.

Parent Responsibilities during Outpatient and Emergency Visits

It may be easy to forget the myriad background duties expected of parents during something as seemingly simple as an outpatient visit. Parents are responsible for scheduling the visit. They are responsible for arranging transportation. In most offices and emergency wards, parents are responsible for filling out all the necessary paperwork, displaying proof of insurance, and handling co-pays. Parents are expected to entertain or otherwise supervise their children while waiting, sometimes for hours, first in a waiting room and then in a patient room. They are expected to provide most or all of the relevant historical information to clinicians

and to assist clinicians in the gathering of additional data, including talking with their child, comforting him or her during examinations or procedures, and helping collect urine or other samples. They are expected to work with clinicians to develop appropriate health care plans, to learn how to execute these plans at home, and to ask any and all necessary questions before leaving. They are then expected to arrange follow-up appointments, fill pharmacy prescriptions, follow through on lab requests, and provide or arrange for transportation home.

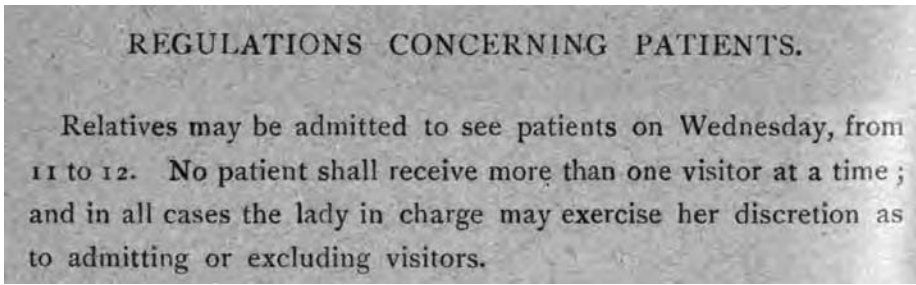
Typical clinician offices, clinics, and emergency wards are completely unprepared to act as surrogates for all or even most of these functions. The current outpatient and emergency systems of health care for children would simply fail to operate without either consistent parental presence or a massive investment in additional staff trained to act *in loco parentis*.

Hospitalizations: Parents as Communicators, Care Coordinators, and Safety Monitors

On the surface, hospitalizations might seem to provide parents with more scheduling freedom than outpatient or emergency ward visits. Technically, hospitals are required to provide round-the-clock care and supervision for their inpatients. In reality, however, although parent responsibilities shift, they diminish only in certain aspects and often increase in others.

Because many inpatient clinicians care for multiple patients simultaneously, communications are notoriously difficult, limited, and haphazard. Parents often need to spend an entire day waiting in their child's room for a chance at one unscheduled five-minute conversation with a physician.

Figure 2. Patient Regulations from the 1896 Children's Hospital (Now Known as Children's Hospital Boston) Annual Report



Source: Courtesy of the Children's Hospital Boston Archives.

During this conversation, parents must be ready to engage fully with the physician in understanding the current clinical status and the anticipated course of illness, ask all the questions they might have, and participate in important health care planning on behalf of their child.

But such planning is only the beginning in an environment that, at the best of times, is confusing and haphazard. A parent who is able to speak with multiple clinicians is likely to find different clinicians saying different and sometimes contradictory things based either on legitimate differences of opinion or on incomplete knowledge or communication. In such instances, parents are often treated as valuable sources of information and care coordination among various clinicians. Moreover, the clinical course of children in the hospital is enormously dynamic. Diagnoses, planned tests and treatments, and prognoses change, sometimes multiple times during a day. Tests are delayed, surgeries are canceled, and emergency situations unfold, often without any timely explanation or warning. In the worst situations, mistakes are made, and mistakes occur frequently.²³ Even with fully staffed nursing and ancillary support from volunteers and child-life

specialists, most hospitalized children spend most of their day with no health care professionals in their room. In such a setting, health care staff fully expect parents to act as an additional, and sometimes essential, line of supervision and safety for their children.

Hospitalizations: Parents as Parents

In addition to fulfilling communication and supervisory roles, parents are also expected to provide emotional support and assistance in ways that health care professionals are simply unable to do. Hospitalized children are often frightened and dependent upon the presence and comfort of their parents. Health care providers often need parents to help their children submit to tests or therapies. This reliance on parental assistance represents a significant shift from hospital policies through the first half of the twentieth century, when parental visiting policies were extremely restrictive.²⁴ For example, an 1896 policy at Children's Hospital in Boston stated that parents were permitted to visit their children for one hour one day a week (figure 2). This approach to parent visits generally persisted in the United States into the mid-twentieth century.²⁵ By the 1960s, however, daily visiting hours had become standard in U.S. hospitals, and by the 1980s,

overnight visits had become commonplace—in 1988, 98 percent of hospitals with pediatric residencies allowed parents to stay with their children twenty-four hours a day.²⁶ This shift was at least partly influenced by a growing body of literature suggesting that child and parent anxiety and emotional distress during hospitalizations may affect how well children recover from their illness.²⁷

Family presence during health care procedures decreases anxiety for the child and the parents. Allowing a parent to be present for the induction of mask anesthesia, for example, may minimize the stress pediatric patients experience undergoing a surgical procedure.²⁸ A study examining whether parental presence during venipuncture altered self-reported distress of the child and parent found that, in the group with parents present, distress scores were lower for both parent and child than they were in the group with absent parents.²⁹ Another small study was conducted to determine whether allowing parents to be present during invasive procedures reduced the anxiety that parents experienced while their child was in the pediatric intensive care unit, to evaluate whether the parent's presence was helpful to the child and parent, and to determine whether the parent's presence was harmful to the hospital staff. Parental presence significantly reduced parental anxiety related to the procedure. Thirteen of the sixteen parents found their presence helpful to themselves, fourteen found their presence helpful to their child, and fifteen would have repeated their choice to watch. Fifteen of sixteen nurses found parents' presence helpful.³⁰ Even in critically acute situations, parental presence has not been associated with negative effects on care. A prospective trial showed that family presence for pediatric trauma patients did not prolong the length of time before CT

imaging was performed or resuscitation was completed.³¹

Parental presence immediately before and after surgery has also been associated with better outcomes. In a randomized controlled trial evaluating the efficacy of family-centered preparation for surgery (that is, using enhanced presurgical parent-child engagement techniques), parents and children in the family-centered care group exhibited significantly lower anxiety before and during induction of anesthesia compared with other groups.³² Another study found that children whose mothers were involved in their post-tonsillectomy care recovered faster and were discharged earlier than children whose mothers did not participate in their care.³³ Likewise, a series of quality improvement studies found that children who had undergone surgery cried less, were less restless, and required less medication when their parents were present and assisted in pain assessment and management.³⁴

Parent Responsibilities during Care at Home

The communication, coordination, supervision, and emotional support that parents are expected to provide during outpatient and emergency visits and hospitalizations are no less pressing when their children are at home throughout their illness, at home after hospitalization, or at home receiving long-term care. For some tasks—particularly supervision—expectations are often greater at home than they would be in a traditional clinical setting. Parents must also take on the added responsibility of providing most or all of the actual health care services the child needs while at home.

Even for otherwise healthy children, health care services can be substantial and complex.

By routinely accepting intensive responsibilities in order to care for their children at home, parents of children with special health care needs suffer under an enormous burden.

For the growing number of children with serious chronic illnesses, however, parents now provide not only medications, but also oxygen, respiratory treatments, feeding-tube care, intravenous nutrition, physical and occupational therapy, and developmental and behavioral interventions, absorbing an ever-growing portion of health care responsibilities through what amounts to generally unacknowledged shadow care. Since the 1990s families whose children are dependent on technology for their care have also become—initially with home health assistance but now often unassisted—operators of complex and expensive devices such as feeding pumps, suction machines, dialysis machines, or ventilators that were previously restricted to inpatient settings.³⁵

A study of families with technology-dependent children found that while the children's health and quality of life benefited from the technology, the time demands of the care routines substantially limited the family's participation in school, employment, and social life in general.³⁶ The need to use certain medical technologies at night also meant that many family members suffered regular disruptions to their sleep.

The study showed that care related to the devices (or “technical care”) was provided mainly by the children's parents, particularly mothers, with varying levels of support from other family members (mainly fathers and older siblings) and formal service providers. Parents and other family members also provided both a large quantity and a wide variety of personal, practical, and other types of care linked to the child's medical condition, in addition to the kinds of care associated with parenting in general.

The technical care involved a range of activities—assisting the child when she or he was using a device; monitoring the child with close visual observation, monitoring devices, or both; managing the equipment (cleaning and preparing it for use, ordering supplies, and managing stocks); maintaining the interface between the device and the body (care of entry and exit sites, placement and replacement of tubes); obtaining technical support from service providers (including hospitals, community services, and companies that supply equipment and consumables); providing technical support to other caregivers through formal or informal training; and preparing equipment for use by other caregivers. These medical tasks had to be performed following strict protocols by parents or other informal caregivers who had been trained in how to manage the devices.

The Parent Burden of Child Illness

By routinely accepting such intensive responsibilities in order to care for their children at home, parents of children with special health care needs face an enormous burden. The additional time and effort they must often devote to finding and managing treatment, attending medical or therapy appointments, and working with day-care providers and schools to find accommodations for their

child's complex and challenging needs can create financial problems, marital discord, sibling issues, and problems at work.³⁷ Across a variety of domains, parental caregivers of children with activity limitations are at a particular disadvantage compared with other parents. They report poorer quality of life, have slightly higher use of sick visits for their own medical issues, and have less favorable employment and financial outcomes.³⁸

Families with chronically ill children have high levels of finance-related family problems. About 40 percent of these families, or about 4 million families nationwide, report experiencing financial problems related to their child's condition.³⁹ Analyses of the 2005–06 national survey of chronically ill children found that 24 percent of their parents reported work loss as a result of their child's health care needs. Greater functional limitations and condition instability were associated with increased odds of family work loss. Illustrating that much of this work loss was in fact illness related, parents reported that having access to a coordinated care system (a medical home, described later) was associated with a 50 percent reduction in the odds of work loss.⁴⁰

A large, nationally representative survey found that children's limitations in taking care of their own personal needs, such as eating, dressing, and bathing, were associated with parents' job changes, income loss, and disruptions in sleep patterns. Functional limitations in mobility and self-care were associated with intensive home-care requirements, leading parents to make various job changes to accommodate these needs. Severe limitations in the child's learning ability greatly increased both job changes and income loss and had a more modest effect on parents' sleep patterns.⁴¹

A study of families of children requiring a tracheotomy found a correlation between the parental care burden and the child's physical health status, as well as between the parental care burden and increasing economic costs associated with this care. A strong correlation was found between the parental care burden and reduced parental mental health status.⁴²

Multiple studies indicate that mothers' careers may be especially affected by caring for children with special health care needs. A study of families with autistic children found that in two-parent households, two-thirds of the parents said the mother's work outside the home was the most affected by their child's autism, with only one-third identifying the father's work or both parents' work as most affected. Three of five mothers had not taken a job because of their child's autism. Of those mothers who were employed, more than half worked fewer hours to care for their child, one-quarter had taken a leave of absence, and nearly as many had turned down a promotion in order to care for their child.⁴³ Another study found that mothers of children with chronic conditions requiring use of technical devices were much more likely to quit their jobs to care for their child. In addition, single mothers were fifteen times more likely than mothers in two-parent families to quit employment.⁴⁴

An article written by the parent of a medically complex child described a typical day in the life of parents like her: "Physicians struggle to determine Sam's diagnosis; therapists struggle to get Sam to reach for that ball, to turn those knees in, to take an unaided step; but we, as parents of a medically complicated child, struggle with much more. I coordinate Sam's medical records so that every physician knows what every other physician is thinking. Most physicians seem grateful for this. I try

to arrange multiple procedures with multiple surgeons on the same day so that Sam will undergo anesthesia as little as possible. Many surgeons seem to want this to happen, but their scheduling staff is not always as accommodating. I consult with our daycare center to determine how Sam can best be served next year in a classroom where everyone is walking but he may not be. I meet with our daughter's teachers to discuss her behavioral problems, possible signs of the stress she feels. I struggle with keeping up with my work when I need to take off so much time to attend medical appointments.”⁴⁵

Some partial strategies have been proposed for relieving parents of some of their care coordination responsibilities. One such strategy is enhancing primary care through establishing patient-centered medical homes (also known as PCMHs).⁴⁶ These medical homes focus on coordinating care and improving communication among clinicians (primary care providers, specialists, nurses) and between clinicians and parents.⁴⁷ This approach relies on an effective referral process and the assignment of clear responsibilities among multiple providers and the patient's family to enable information exchange, facilitate joint decision making, and prevent misunderstandings.⁴⁸ Studies have demonstrated that poor care coordination between primary care providers and specialists leads to delayed access to care, inferior quality of care, ineffective use of resources, inflated health care costs, and dissatisfaction among patients and providers.⁴⁹ Another strategy is the concept of global payment, in which primary care, subspecialty care, and inpatient care are integrated and payment is “bundled” as a lump sum for each patient or episode of illness. Such systems would require creating networks of primary care providers, specialists, and hospitals that

would benefit from developing close working relationships. Many of the models for “accountable care organizations” envisioned in the Patient Protection and Affordable Health Care Act may incorporate concepts similar to patient-centered medical homes and global payment.

Investing in and enhancing community-based resources, such as school-based health centers, might also help reduce the parental burden of child illness by providing a secondary source of care in a location where children already spend much of their time, thus allowing parents to stay at work occasionally while their child's minor health care needs are addressed (or leave work for less time because they do not have to transport their child between the school and the clinic). Currently, school-based health centers vary widely in the comprehensiveness of the services they provide. If such centers were regularly staffed by some combination of nurse practitioners, physicians, clinical social workers, psychologists, nutritionists, dentists, or dental hygienists, they could potentially provide a variety of routine preventive and minor acute or chronic care services.

The Employer Perspective

Although the child health care burden on parents can be enormous, the burden of parent absences on employers can also be substantial. The costs to employers of unplanned or unscheduled absences by all employees are estimated at 9 percent of payroll, and the total costs, direct and indirect, of all major absence categories average 35 percent of base payroll.⁵⁰ Employers, therefore, have clear stakeholder interests in parents' decisions regarding employment and leave.

Employers seek to avoid costly or unnecessary disruptions to essential operations. Even

when parent absences are unpaid, they have the potential to create disruptions that can be rectified only by the costly hiring and training of temporary employees or the shifting of work responsibilities to existing employees at the potential expense of less critical but still important activities. Department of Labor estimates suggest that employee absences cost U.S. businesses \$100 billion a year in lost productivity.⁵¹ Thus, employers may have an incentive to discourage or prevent parents from leaving work to tend to their child's health care needs. Moreover, workplace benefits are inherently at risk for at least some level of abuse by employees. According to some estimates, only 34 percent of all unscheduled absences are related to employee illness, while 22 percent are related to family issues, such as caring for children or dependent parents.⁵² In addition, a survey of 450 human resources professionals found that suspected employee abuse of intermittent leave taken under the FMLA was the primary FMLA-related concern for employers, and that the potential for or suspicion of abuse was reported to cause extreme difficulty in 42 percent of the organizations surveyed.⁵³ A separate survey showed that 47 percent of employers felt that unjustified intermittent leave posed at least "somewhat of a problem" for their operations.⁵⁴ Therefore, employers also have incentives to institute reporting and medical necessity requirements, as well as waiting periods and other restrictions to discourage abuse.

Disruptions to operations can come in several forms. Employers that do not provide parents the opportunity to care for their sick children can find that they permanently lose skilled employees, are unable to recruit highly qualified workers, and suffer a loss to workplace morale, all of which can create serious disruptions. Moreover, evidence is

accumulating that employees who continue to work but are distracted by personal issues may create productivity losses of their own ("presenteeism" as opposed to "absenteeism") that may reduce some of the benefit to employers of preventing parent absences in the first place.⁵⁵ In this context, employers have some incentive to accommodate parent absences, assuming that employers can find ways to protect themselves from productivity loss or its financial consequences.

What Do Parents and Employers Need?

In a world in which employment and leave benefits could be written *de novo* to best suit parents and their employers, what benefits would best help parents fulfill all of the expectations placed on them with respect to their children's health care needs while limiting negative effects on their employers?

All parents would benefit from some negotiable number of days or portions of days that would allow them to schedule their children for routine preventive care visits assuming adequate advance notice is given. In addition, all parents would benefit from some negotiable number of discretionary days requiring no advance notice that could be used in the event of unpredictable but relatively minor acute illnesses. How employers would accommodate such discretionary days is unclear. Employers are substantially less able to shield themselves from productivity loss when advance notice is impossible than when it is given. Therefore, employers would need some way of insuring themselves against the risk of productivity loss.

Beyond scheduled and discretionary days, however, are two additional scenarios, each of which would not only require a greater investment of resources but also pose greater

threats to parent employment—as well as to parent and child health and well-being. First is the scenario in which an otherwise healthy child suffers an acute illness such as severe pneumonia requiring admission to an intensive care unit; the child is expected to recover fully but also to require an extended period of intensive parental caregiving. In this situation, parents would need the ability to take off a large block of time with no advance notice or to shift temporarily to part-time work and transition gradually back to full time without set start or finish dates. Ideally, pay loss during this period would be limited. There would also be some level of guaranteed job retention so that employees could not easily be replaced permanently during extended absences. From the employer standpoint, all of these conditions might generate substantial costs. The need to accept indeterminate start and end dates without advance notice and the need to allow gradual transitions back into a guaranteed-retention position create substantial uncertainty and inefficiency that the employer would need to absorb. Meanwhile, preservation of pay would be a direct additional cost of parent absence. Again, employers would need some way to insure themselves against these risks. In some cases employers might also benefit from help in designing or implementing workflow innovations that could accommodate flexible or alternative schedules and locations.

The second and even more challenging scenario is the one in which a child suffers from a serious chronic illness. It is these situations in particular that would require maximum flexibility. Because children with special health care needs have more scheduled and unscheduled health care encounters, and greater overall care needs at home, than other children, their parents would need access to more time off both with advance

notice and without. In addition, absences for parents of chronically ill children may be brief or extended, continuous or intermittent; may switch from one type to another unpredictably; and are often broken up by periods of relative health. For employers, this scenario would seriously raise the question of whether keeping an employee would be worth any amount of insurance, subsidization, or flexibility. In this case, both parents and employers would have strong incentives for parents to downshift from full-time to part-time work or to simply leave the workforce. Unfortunately, in many cases, these are exactly the same parents who would suffer most from loss of income associated with downshifting or job loss.⁵⁶ How employment and leave benefits can be arranged to meet the needs of this population is a critical issue, one for which policy makers and employers have yet to find a comprehensive solution.

Types of Parent Support

Employed parents in the United States tend to rely on a haphazard mix of support to care for their children's health needs, including federal, state, and local leave laws and programs. The extent to which parents can care for their children's health is largely determined, however, by their working conditions, including flexibility in duties, locations, and schedules, as well as other employer-provided benefits. In the United States, where the availability of paid sick leave is limited, parents who have paid sick days are more than five times as likely to be able to care for their sick children themselves as parents who do not have paid sick leave.⁵⁷ According to the 2010 National Paid Sick Days Study, about 64 percent of all workers report that they are eligible for paid sick days from their employer (including those receiving "paid time off" days, also known as PTO days, which combine time off for sick leave,

vacation, and other reasons).⁵⁸ However, only 47 percent of workers receive paid sick days that they can use for sick family members. Without flexible scheduling or paid leave to care for children's health needs, employed parents may forgo disease prevention activities or experience wage and job loss when they take time off to seek or provide care for their children. For example, studies in Haiti, Indonesia, and the United States have found that parents report work schedule conflicts as a significant barrier to getting their children immunized.⁵⁹ Among U.S. workers with paid sick days, 14 percent have sent a sick child to school or day care; among those without paid sick days, 24 percent have done so.

Federal Support

The federal government guarantees unpaid leave to some workers but does not mandate paid leave. The federal FMLA provides up to twelve weeks a year of unpaid leave with job protection (that is, protection from being fired) to certain workers to care for themselves or ill family members.⁶⁰ The FMLA also requires that an employee's group health benefits be maintained during the leave. Signed into law in 1993, the FMLA was the first federal leave legislation to address the competing demands of work and family. About half (47 percent) of workers are eligible for FMLA leave;⁶¹ eligibility depends on the size of the employer (fifty or more employees), the number of hours worked, and the duration of current employment (at least 1,250 hours for the same employer in the past twelve months). Many employees, however, cannot afford to take unpaid leave. Of the 3.5 million employees who needed but did not take leave in 2000, 78 percent cited inability to afford leave as a reason. Of these, 88 percent said they would have taken leave if they had received either some pay or (if already receiving partial pay) additional pay.⁶²

Two pieces of proposed federal legislation, the Healthy Families Act and the Family Leave Insurance Act, would partially address concerns about employees who lack access to paid leave that can be used to care for themselves or family members. The Healthy Families Act would create a new national standard guaranteeing employees one paid hour off for each thirty hours worked and enabling them to earn up to seven paid sick days a year that they could use for the health needs of themselves or family members. It would also be available to more workers than the FMLA is, because it applies to employers with at least fifteen employees and has lower hour requirements. Costs would primarily fall upon employers, who would be responsible for paying employees' wages when they use their sick leave. The Family Leave Insurance Act would create an insurance program, funded through employer and employee payroll tax contributions, to provide up to twelve weeks of paid FMLA benefits. Employees would receive a specified percentage of their daily earnings and be subject to a waiting period of five workdays before receiving benefits. The Family Leave Insurance Act would also have somewhat broader eligibility than the FMLA: it would apply to employers with twenty or more employees (as opposed to fifty or more) and to employees who have worked at least 625 hours for the same employer in the past six months (compared with 1,250 or more in the past twelve months).

Research shows general public support for government-mandated paid sick days. According to a nationally representative study in 2010, across all sociodemographic and political groups, the majority of Americans believe that paid sick leave to care for themselves or for immediate family members

Table 1. Comparison of Federal and State Family Leave Programs

Provision	Federal		State	
	Family and Medical Leave Act	Family Leave Insurance Act (proposed)	California: Paid Family Leave Insurance Program	New Jersey: Family Leave Insurance Program
Length of leave	12 weeks	12 weeks	6 weeks	6 weeks
Leave is paid	No	Yes	Yes	Yes
Benefit structure	n.a.	Specified percentage of daily earnings	55 percent of weekly wage up to a cap	66 percent of weekly wage up to a cap
Maximum benefit (2010)	n.a.	n.a.	\$987/week	\$561/week
Offers job protection	Yes	Yes	No	No
Employer contribution to pay	No	Yes	No	No
Part-time workers eligible for benefits	Yes*	Yes*	Yes	Yes
Workers in companies with under 50 employees eligible for benefits	No	Yes	Yes	Yes
Waiting period before benefits can be used	No	5 workdays (but no more than 7 calendar days)	7 days**	7 days**

Source: Authors.

n.a. = Not applicable.

*Employees are eligible for FMLA if they have worked at least 1,250 hours for the same employer in the past twelve months. The Family Leave Insurance Act would apply to employees who have worked at least 625 hours for the same employer in the past six months.

**In California and New Jersey the seven-day waiting period refers to seven days of caring for an ill family member. The seven days do not have to be consecutive and can be served regardless of whether the claimant is scheduled to work on those days (weekend days included).

should be a government-guaranteed right for workers.⁶³ Sixty-nine percent of respondents said that paid sick days were “very important” for workers, and 75 percent favored a law that guarantees paid sick days for all workers.

State or Local Support

In 2004 California attempted to extend the FMLA’s approach by instituting the Paid Family Leave Insurance (PFLI) program, which uses a payroll tax to create an insurance pool with broad eligibility that partially funds up to six weeks of leave for a child’s (or other immediate family member’s) illness or a child’s birth or adoption.⁶⁴ The PFLI covers most part- and full-time employees at about 55 percent of their salary up to a maximum in 2010 of \$987 a week;⁶⁵ it does not, however, include job protection. Benefits apply after employees miss one week of work for a given

illness (continuously or cumulatively). A statement signed by a physician or other clinician documenting the illness is required. New Jersey implemented a similar law in 2009. Washington state passed more limited family leave legislation (covering leave only for parents with a newly born or newly adopted child) in 2007 but has yet to implement its program.⁶⁶

In addition, several states, including California, Connecticut, Hawaii, Washington, and Wisconsin, have flexible sick leave laws that entitle all workers who have access to sick leave to use some of their sick days to care for a sick child.⁶⁷ A few cities, including San Francisco (2006), the District of Columbia (2008), and Milwaukee (2008), have also passed sick day ordinances that guarantee paid sick days for all or most

Table 2. Comparison of Federal and Local Paid Sick Leave Programs

Characteristic	Federal	Local		
	Healthy Families Act (proposed)	San Francisco	District of Columbia	Milwaukee
Maximum number of paid sick days per year	≥15 employees: 7 ≤14 employees: 0	≥10 employees: 9 ≤9 employees: 5	≥100 employees: 7 25–99 employees: 5 ≤24 employees: 3	≥10 employees: 9 ≤9 employees: 5
Benefit structure	1 hour of paid sick leave for each 30 hours worked	1 hour of paid sick leave for each 30 hours worked	≥100 employees: 1 hour/37 hours worked 25–99 employees: 1 hour/43 hours worked ≤24 employees: 1 hour/87 hours worked	1 hour of paid sick leave for each 30 hours worked
Employer contribution to pay	Yes	Yes	Yes	Yes
Sick days can be used to care for family members	Yes	Yes	Yes	Yes
Part-time workers eligible for benefits	Yes	Yes	Yes	Yes
Workers in companies with under 50 employees eligible for benefits	Yes	Yes	Yes	Yes

Source: Authors.

workers.⁶⁸ Legislators in other states and cities are also working on paid leave initiatives, and there are ongoing congressional efforts to pass the Healthy Families Act. Tables 1 and 2 compare the provisions and characteristics of these various laws and proposals.

Employer-Provided Support

Employers, meanwhile, provide a patchwork of formal and informal solutions to support parents, including sick days (often used for children without explicit employer approval, which can place parents at risk for termination); flexible paid time off that combines vacation, sick time, and family leave; telecommuting; and programs that allow employees to donate or share unused paid leave days. Individual supervisors and coworkers also use their discretion to informally enable parents to leave work for hours or days (as in “Just go, and I’ll cover for you,” or “Just go, and you can make the time up later”).

Employees caring for dependent family members face complex challenges in their personal and professional lives. When the dependent is a child with special health care needs, workplace programs can help families more effectively use employee benefits and access public and private resources.

Employee assistance and work-life programs are particularly well suited for addressing the needs of these employees and their children. In 2005, for instance, investigators examined how three separate large U.S. employers implemented programs specifically for employees with chronically ill children.⁶⁹ Their approaches included establishing a parent network, independently testing and refining the company’s employee assistance program/work-life resource and referral service to better serve these parents, helping to guide employees when choosing health plans, and coordinating the company’s clinical services with public programs to assist families with chronically ill children. The

employers reported a positive impact on employee retention and commitment, improved use of employee benefit programs, and improved promotion of corporate diversity objectives.

International Comparisons

The United States is one of only a few industrialized countries that do not have national laws providing paid leave for children's health needs. At least forty-three countries, including Australia, Canada, France, Japan, Nicaragua, and South Africa, specifically guarantee parents some type of paid leave when their child is ill, and more than half of the forty-three provide full wages.⁷⁰ Although length of leave varies, an analysis of thirty-seven countries that offer paid leave for children's health needs found that fourteen guarantee eleven or more days of paid leave, six give seven to ten days, and ten give one to six days.⁷¹ Types of paid leave arrangements also vary. For instance, El Salvador provides up to fifteen days for serious illness or injury of a child, while Norway typically provides ten days annually as a base, fifteen if the employee has more than one child, and twenty if the employee has a chronically ill child. In addition, at least thirty-four countries guarantee discretionary leave (seventeen with pay) that can be used for ill children.⁷²

Countries that offer paid leave for children's health needs use different methods of negotiating and administering their paid leave benefits, but cost-sharing between employers and the state is common. For instance, Denmark has traditionally used collective agreements to determine most of the benefits available to workers, with employment laws focused mainly on establishing rules for collective bargaining and enforcing agreements.⁷³ Lately, however, the Danish government has moved more toward directly applying

statutory requirements to employers. Under most circumstances, the Danish law requires the employer to pay the cost of paid-leave benefits for the first two weeks of a period of absence; any remaining costs are paid by the claimant's residential local authority, a decentralized municipality that imposes taxes and also receives funds from the state.⁷⁴ In contrast, Sweden establishes employment standards primarily through laws rather than collective bargaining, despite high levels of unionization.⁷⁵ Like Denmark, though, the cost of benefits is divided between employers and the state's social security system, with employers paying during an initial period, and the social security system covering the remainder.⁷⁶ The same is true of Poland.⁷⁷

Addressing Gaps in Existing Leave Policies

Current state and federal leave policies in the United States cover some but not all parents and employers, and among those covered, the policies address some but not all of their needs.

FMLA

For parents, the FMLA provides job protection benefits, which parents may need for unscheduled or extended absences, and it allows up to twelve weeks of leave annually, which likely covers the leave needs for parents of all but the sickest children. It also requires that any group health benefits an employee has be maintained during leave. Moreover, the FMLA does not require advance notice (although it does require justification if notice is not given at least thirty days before taking leave), and leave can be taken intermittently, which creates the flexibility that is crucial for parents of children with special health care needs. The FMLA, however, has two critical weaknesses for parents that clearly suppress use. First,

eligibility is essentially restricted to long-term, more-than-half-time employees of public agencies and large private employers, a group that includes fewer than half of all employees.⁷⁸ Second, the leave is unpaid, which means many parents cannot afford to make use of the benefit.

PFLI

California designed the PFLI program to extend the FMLA's provisions in two important ways. First, it greatly expands eligibility, especially to employees in small organizations. Because the PFLI is tied to the state disability insurance provisions, it covers most employees in the state. Two major exceptions are self-employed individuals and employees covered by collective bargaining agreements that waive disability insurance. Second, the program provides pay, albeit partial, during leave (55 percent of salary up to a maximum of \$987 a week in 2010).⁷⁹ Moreover, it retains some of the features of the FMLA, including not requiring advance notice and allowing leave to be taken intermittently.

The PFLI, however, like the FMLA, has provisions that discourage uptake. First, the lack of full pay during leave prevents use for many parents.⁸⁰ The PFLI is also limited to six weeks rather than the twelve weeks guaranteed by the FMLA. Although it does not require advance notice, it does require one week of missed work (or accrual of seven days if missed intermittently) for an illness during the year before the benefit period can start, which reduces its usefulness for limited absences. It also does not include the FMLA's job protection provision (although FMLA-eligible employees can simultaneously access job protection under the federal law), which raises the risk of job loss for parents who have frequent and extended absences to tend to their chronically ill children. The PFLI does

not require employers to maintain employees' employer-sponsored health benefits during leave, an especially important consideration for parents of children with special health care needs. Finally, the PFLI has far less stringent employee notification requirements than the FMLA and did not benefit from the same kind of aggressive public education roll-out campaign that the FMLA enjoyed. The FMLA was accompanied by a two-year Department of Labor publicity campaign and strong mandatory requirements for dissemination of FMLA information in workplaces. The PFLI was not widely publicized and requires only that employers provide information to new employees and employees who inquire about pay during their leave for a covered purpose. As a result, many employees must either know about the PFLI before requesting it or request it before knowing that they could receive pay. Given these structural limitations and weak dissemination requirements, it is not surprising that awareness of the program among parents of chronically ill children has been low (18 percent about eighteen months after implementation), and use has been almost nonexistent (5 percent).⁸¹ Awareness was only slightly higher for the general California population: 28 percent were aware of the program in 2007.⁸²

Despite these limitations, PFLI sets an important and innovative precedent. By using an insurance model to create a benefit funded entirely by employee contributions, the PFLI simultaneously attempts to avoid social stigma associated with welfare benefits and to address one of the key cost concerns of employers—providing pay during leave. It also raises the possibility that, just as employees' contributions to an insurance fund could provide parents with some measure of financial protection in the event of child health-related absences, employer

contributions (or even additional employee contributions) to a similar fund could protect employers from other costs of parent absences (such as the cost of a temporary replacement).

What Might a National Paid Family Leave Policy Look Like?

The elements of the FMLA and PFLI that are most useful to parents, as well as innovations designed to protect employers, could be combined to create an outline for a national policy aimed at addressing the needs of both parents and employers. The FMLA has some clear advantages for parents, including job and health insurance protection, twelve-week duration, no advance notice requirement, no waiting period, and the ability to be used intermittently. The PFLI adds much broader coverage and pay. Bringing these strengths together would likely address many parents' most pressing needs across all types of absences, from scheduled limited absences to unscheduled extended ones (although partial pay will remain a disincentive for some). Parents of chronically ill children who are at highest risk of job loss and severe financial consequences could have access to benefits that might protect them from being forced to permanently leave the workforce.

On the employer side, the enhanced benefit would likely need to be balanced by both antifraud protections and financial protections against the costs of employee absences. Strong reporting and illness verification

requirements coupled with the ability for employers to require employees to first use other employer-provided benefits such as paid vacation could provide some protection against abuse. With respect to costs of the absence itself, PFLI benefits in California are entirely funded by employee contributions, with employers absorbing other costs, and a recent study documented little hardship for employers.⁸³ Thus, some type of cost-sharing between employees and employers would seem reasonable in a national policy framework.

Ultimately, the reasons to implement a national policy reflect multiple perspectives. First, mothers and fathers nationwide might receive a measure of security that could help them to participate more fully in the workforce while also engaging in the care of their children, regardless of their children's health or illness. Second, employers might have fewer disincentives against promoting family-friendly workplace policies, and a strong uniform policy might reduce employer concerns of competitive disadvantage created by an unlevel playing field. Third, the child health care system, operating in conjunction with a standardized system of benefits, might be able to more easily understand and cope with the limitations of the parental shadow system of care upon which it depends. Finally, nearly all children—even those not chronically ill—would surely benefit from having greater parental presence protecting and supporting them in times of need.

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