PERSPECTIVE

An audio interview with Dr. Hong is available at NEJM.org

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TOWARD INCREASED ADOPTION OF COMPLEX CARE MANAGEMENT

Caring for a Sick Child — Why Family-Leave Policies Matter

Mark A. Schuster, M.D., Ph.D., and Paul J. Chung, M.D.

Health care providers and public health officials routinely recommend that acutely ill children stay home from school and, if necessary, see a clinician. Otherwise, their illnesses can worsen or spread to others, health care costs can increase, and small problems can become serious threats. But for many employed parents, taking time off to care for a sick child means losing income or, worse, risking their job.

“A mother deserves a day off to care for a sick child... without running into hardship — and you know what? A father does, too,” President Barack Obama said during his 2014 State of the Union address. The conflict between protecting personal and public health and paying the rent and the grocery bill was highlighted during the 2009 H1N1 influenza pandemic, when government officials asked parents to keep their sick children home, only to find that millions of employed parents simply couldn’t.

Even without a pandemic, similar stories play out throughout the United States every day. Consider a mother who knows both how to assess her son’s asthma symptoms and when he needs to see a clinician. If his medicine doesn’t seem to be working on a weekend or at night, they go straight to the clinic, he receives treatment, and they avoid a hospital admission. But when the boy has an asthma attack on a weekday morning, his mother sends him to school, fearing that missing work will mean losing her job. Three times in 18 months, when she waits until after work to bring him to the clinic, his asthma worsens, and he ends up hospitalized. Each time, what should have been 3 hours in the...
Or consider a young girl with a fever and flu-like symptoms who is given Tylenol and sent to school by her father because he can’t miss work. Two days later, the girl develops the rash characteristic of fifth disease on her cheeks. Her whole class has been exposed, and because the teacher is pregnant, her fetus is now at risk. Paid sick days could help families and communities avoid such consequences. According to a 2010 national study, employees who receive paid sick days are substantially less likely than employees without such benefits to send a sick child to school.

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### Comparison of Federal and Selected State Family-Leave Programs.

<table>
<thead>
<tr>
<th>Provision</th>
<th>Federal</th>
<th>Family and Medical Insurance Leave Act (proposed)</th>
<th>California Family Leave Insurance Program</th>
<th>New Jersey Family Leave Insurance Program</th>
<th>Rhode Island Temporary Caregiver Insurance Program</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length of leave</strong></td>
<td>12 wk</td>
<td>12 wk</td>
<td>6 wk</td>
<td>6 wk</td>
<td>4 wk</td>
</tr>
<tr>
<td><strong>Leave is paid</strong></td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Benefit structure</strong></td>
<td>NA</td>
<td>66% of weekly wage up to a cap</td>
<td>55% of weekly wage up to a cap</td>
<td>66% of weekly wage up to a cap</td>
<td>Weekly rate of 4.62% of wages paid during highest quarter of prior year</td>
</tr>
<tr>
<td><strong>Maximum benefit (2014)</strong></td>
<td>NA</td>
<td>$1,000/wk</td>
<td>$1,075/wk</td>
<td>$595/wk</td>
<td>$752/wk</td>
</tr>
<tr>
<td><strong>Offers job protection</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Employer contributes to pay</strong></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Part-time workers eligible for benefits</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Workers in companies with &lt;50 employees eligible for benefits</strong></td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Waiting period before benefits can be used</strong></td>
<td>No</td>
<td>5 workdays (but no more than 7 calendar days)</td>
<td>7 days</td>
<td>7 days</td>
<td>7 days</td>
</tr>
</tbody>
</table>

* NA denotes not applicable. In California, New Jersey, and Rhode Island, the 7-day waiting period refers to 7 days of caring for an ill family member. The 7 days do not have to be consecutive and can be counted regardless of whether the claimant is scheduled to work on those days (weekend days included). In 2007, Washington State passed paid-family-leave legislation that would provide parents with up to 5 weeks of paid leave in the event of childbirth or adoption, but the program has not yet been implemented.

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Have to monitor and clean devices, order supplies, replace tubes, obtain technical support for malfunctioning machines, train other caregivers, and on and on. Indeed, ever since Medicare began, in 1966, to promote home health care alternatives in part to reduce hospital costs, there has been a gradual (and now accelerating) shift in the degree to which hospitals transfer care and costs to the homes and hands of parents, who have often been only marginally trained for their duties. At some point, continuing to give parents additional responsibilities without providing them with more time and resources for meeting those responsibilities may backfire, leading to increases in return visits to the emergency department, hospital readmissions, morbidity, mortality, and health care costs. If we want to improve such...
TIME OFF TO CARE FOR A SICK CHILD

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outcomes by providing better discharge preparation, for instance, parents need to be available to receive discharge training, ask questions, demonstrate their understanding, and practice their skills, and they need to be given the time necessary to implement at home what they've learned at the hospital. These parents need more than “just a day off.” They need to be able to meet their children's postdischarge health care needs without risking their job.

Our research has shown that parents have a substantial unmet need for leave to care for chronically ill children. Those who took leave (whether paid or not) believed that it had positive effects on their child's physical and emotional health. But staying home strained their finances (especially with unpaid leave) and threatened their job security. Of parents who took leave, 40% reported returning to work sooner than was appropriate for their child.3

Parents' options for both short-term and long-term family sick leave depend on where they live and work. Government approaches include mandating unpaid family leave with job protection (protection from being fired) for extended absences, paid family leave with or without job protection for frequent or intermediate-length absences, and paid sick days and kin-care leave that can be used for incidental brief absences to care for ill family members. Nationally, the Family and Medical Leave Act guarantees employees of large employers 12 weeks of job-protected unpaid leave to care for ill family members, but less than half of U.S. employees are eligible (see table). California, New Jersey, and Rhode Island have passed various forms of paid-family-leave legislation, with employees funding leave through payroll deductions to statewide pools. Some states and municipalities require employers to offer kin-care leave, and some, including Connecticut, New York City, San Francisco, and Washington, D.C., among others, require employers to offer paid sick days (see Table S1 in the Supplementary Appendix, available with the full text of this article at NEJM.org). More than a dozen other states and municipalities are considering paid-sick-days legislation. Federally, the proposed Healthy Families Act (H.R. 1286, S. 631) would allow employees to earn up to 7 days of paid sick leave, and the proposed Family and Medical Insurance Leave Act (FAMILY Act, H.R. 3712, S. 1810) would guarantee up to 12 weeks of paid family leave.5

About half of U.S. employees do not receive any paid sick days that they are allowed to use to care for family members.1 When parents without such sick days stay home from work to care for an ill child, they can be fired or otherwise penalized. Some employees try to minimize that risk by claiming that they themselves are ill when they stay home with their ill child, and sometimes supervisors and colleagues informally cover an employee's absence without reporting it. Flexible schedules and telecommuting can help, especially for parents with a chronically ill child. Although some employers have raised concerns about potential misuse of paid-sick-leave benefits, the risk of fraud can be minimized through employer policies requiring certification of health conditions. Furthermore, studies have shown that most employees use these types of benefits to deal with the real demands of real illnesses. And the health care system relies on parents to meet these demands on behalf of their children.

Back in 1896, a sign at Children's Hospital in Boston read, “Relatives may be admitted to see patients on Wednesday, from 11 to 12.” Today, signs in U.S. hospitals would be more likely to read, “Relatives are welcome 24 hours a day, 7 days a week. We need you!” If we expect parents to partner with health care providers to improve children's health outcomes and reduce health care costs, we will need to help parents, employers, and governments figure out how to make that happen. At the intersection between health and work, the health care community needs to provide a voice for patients and their families.

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