

The Care Gap

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A care gap exists when people who need care receive substandard care or no care at all. No one has previously tried to calculate the size of the overall care gap in the United States. We can approximate its size by subtracting the number of people receiving adequate care from those needing care, and counting the number of people that remain. But the gap is difficult to measure accurately, both because much of the care work performed in our society is unpaid and invisible, and for the more prosaic reason that no national survey has provided good direct measures of care adequacy.

“Care” involves money, as well as paid and unpaid work. For example, a child needs food (money), may be in a child care center for part of the day (paid work), while parents are responsible for the child much of the time (unpaid work). To think about the “care gap,” we need to separate able-bodied adults, who will only occasionally need care, from those who need care on a more regular basis—specifically children and adults with disabilities. The mixture of financial resources, and paid and unpaid work required to care for these individuals varies—compared to an infant, a teenager typically is more costly in terms of money and less so in terms of parental time.

Even though care is complicated and care needs are diverse, we require some indicators for whether care for those in need is adequate if we are to understand, and close, the care gap. For adults who may become seriously ill or injured, and for our children, closing the care gap can be viewed in part as a matter of productivity. Young people who receive adequate care are more likely to become productive adults, and many injured, ill or disabled adults can achieve or return to a productive life with proper care. But closing the care gap is more centrally a moral imperative: in any conceivable vision of a good society, we would not allow children to grow up in the midst of grinding poverty or to be latchkeyed for much of their young lives, nor would we allow adults who cannot care for themselves to face privation and, in some cases, preventable death. We can and should do better.

Fortunately, beginning with the 2000 Census, we have reasonable indicators for how many individuals in the U.S. need care. That year, the Census Bureau began collecting figures on disabilities, so if we assume those in need of care include all children, along with adults with disabilities, then we can calculate the total number of individuals needing care. Although some individuals with disabilities may not need care on a regular basis, the vast majority do. In the age 16 to 64 group, over half report difficulties with employment, while one-quarter of that

¹ This material is largely drawn from *Striking a Balance: On Work, Family and Life*, by the author, and forthcoming from Dollars & Sense.

group reports difficulties going outside of the home, a figure that is much higher among the elderly disabled.

According to the latest American Community Survey, for 2004, our total population of just over 284 million included over 64 million children under the age of 16, and 35 million adults with disabilities. So just under 100 million people, or 34.9 percent of Americans require some level of care. Those needing care are concentrated among the young and the elderly, partly because we view all children as needing care, but also because only 11.6 percent of adults aged 16 to 64 report disabilities, while over one-third of adults over the age of 64 have disabilities (see Table 1).

There is no single indicator for the adequacy of the time and money being provided as care to these groups, but we start with the simple indicator of poverty. Living in poverty and either being a child or having a disability is a particularly toxic mix in the U.S. For example:

- The Child Care and Development Block Grant program, our national effort to provide child care for the children of working mothers in poverty, *assists only one out of every seven eligible children*, with Head Start serving only three out of every five eligible children (CDF 2005).
- Children born into poverty are eight times more likely than others to go hungry, are almost three times more likely to have no regular source of health care, and are 1.6 times as likely to die in infancy (CDF 2004).
- Under Medicare, the universal health insurance program for the elderly and certain others, interviews with home health aides revealed many of them were visiting patients on their days off in order to provide services not covered by the program—including long-term care (Stone 1999). These attempts by paid providers to close the care gap through the provision of unpaid work signals the desperate need for—and lack of—greater governmental supports.
- Federal funding for Medicaid, the health insurance program for the poor and disabled, has been slashed relative to Medicare. In Michigan, the underfunding of Medicaid reached \$950 million by 2005, with doctors receiving only around 60 percent as much as for the same services provided under Medicare, and hospitals receiving 73 percent as much. Doctors are increasingly turning away Medicaid patients, and hospitals are not even covering the costs of treatment (MSMS 2005).
- As individuals with disabilities were moved out of institutional facilities during the 1980s and 1990s, federal funding for housing did not increase accordingly, leaving *an estimated 1.8 million individuals with disabilities in need of but not receiving federal housing assistance* (CCD 1996).
- Individuals who become disabled due to an injury at work must wait 29 months before receiving health coverage through Medicare; *an estimated four percent of these individuals die while on the waiting list* (IDSA 2004).
- To make matters worse, in early 2006 the Bush administration successfully pushed through \$39 billion in cuts to domestic programs. The cuts to Medicaid alone would affect 13 million of the nation's poor, and mainly children. The cuts will also dramatically reduce the collection of child support payments, and college student loans (CNNMoney 2006). The administration then proposed further cuts for 2007 and beyond, including cutting off food stamps for 300,000 individuals, cutting other food assistance

for 420,000 low-income elders, eliminating child care supports for 400,000 children, and slashing an additional \$13b from Medicaid (NWLC 2006).

There is perhaps some justification for allowing able-bodied adults to live in poverty. Many, and perhaps most, Americans believe that adults capable of earning a living should do so. But this argument fails when we turn to those in need of care.

The American Community Survey also provides poverty rates among adults with and without disabilities. Combining these figures with those for 2004 from the Current Population Survey for poverty rates among children, we can estimate the poverty population among those needing and not needing care. Among the approximately 100 million Americans needing care, almost 19 million individuals lived in poverty that year. Out of the 185 million adults not in need of care, just over 18 million people experienced poverty. In other words, the odds of living in poverty are twice as high for those in need of care. Looked at differently, *over half of all Americans living in poverty are either children or adults with disabilities.*

As disturbing as this is, there are good reasons to believe the official poverty rate is too low, and does not capture income levels most of us would consider socially adequate. Specifically, the rate may be set below the level needed to provide care, such that the standard poverty measure leads us to underestimate the care gap. Researchers at the Economic Policy Institute propose an alternative indicator of poverty based on a basic family budget (Boushey et al 2001). This measure differs from the official poverty standard mainly by accounting for increases in rents and incorporating factors not included in the official rate, such as health insurance and telephones. Most of us don't think of a telephone as a luxury, particularly if it is a single land-line, and health insurance is part of any conception of an adequate standard of care. This benchmark suggests that official statistics underestimate the percentage of families with children living in poverty by approximately 150 percent in the population as a whole. The extent of underestimation is likely even more severe among those needing care because a disproportionate number in this group fall below the official poverty line. By extension, many in need of care are likely hovering just above the official poverty rate. A reasonably conservative statistical strategy therefore involves increasing the percentage estimated to need care by 150 percent. According to this alternative calculation, *at least 47.5 percent of those who need care—or over 47 million individuals—cannot afford such basic necessities as health insurance or quality child or elder care.*² Looked at differently, 16.6 percent of the overall population is subject to a care gap in which a need for care coincides with insufficient income.

For the remaining 52.5 percent of individuals who need care and whose families can afford it, there is reason to believe that paid care services are largely inadequate. For example, studies demonstrate that parents with sufficient income favor center-based child care.³ However, even parents with sufficient resources to afford formal, center-based child care find that low quality is pervasive. The National Council of Jewish Women (1999) released reports in 1972 and again in 1999 on the quality of child care in the United States. The most recent report found a full 80 percent of child-care centers are mediocre to poor and that turnover of staff averages more than 30 percent per year. Such high turnover is disturbing because it means our youngest

² To reach this figure, the 17.7 percent figure is multiplied by 2.5, effectively raising it by 150 percent.

³ Many studies show that higher incomes are associated with less relative and informal care, and with more center-based care. Studies that control for the possibility that poor parents may prefer relative or informal care nonetheless find that these parents would tend to switch to center-based care if it were affordable. See Gornick and Meyers (2003, pp. 193-194).

children often wake up in the morning not knowing who will care for them during much of the day. It also means care providers frequently have little knowledge of a child's specific needs.

For older children, after school programs have become a needed alternative to self-care, and a way to enhance their educational opportunities. Here quality is not so much an issue as quantity. A 2002-2003 nationally representative study estimated that only 6.5 million children from grades kindergarten through 12 are enrolled in after school programs, but an additional 15 million youth would enroll if the programs existed and were affordable (Afterschool Alliance 2004).

At the other end of the age spectrum is elder care, where a recent government funded report suggests quality is worse in nursing homes than in child care centers. The report found 90 percent of nursing homes exhibiting staffing levels so low that they create dangerous conditions for those who live there (Abt Associates 2001).

There is little information available on the quality of paid care for adults with disabilities but, to the extent these mirror the far more visible arenas of nursing homes and child care centers, the quality is probably poor in most of cases.

Of course, much care is provided in the form of unpaid work—by mothers, fathers, sons, daughters, and community members. Nonetheless, given the vast majority of child care centers and nursing homes are of substandard quality, while less than half the demand for after-school programs is being met, an extremely conservative estimate of the care gap would add at least three percent to the poverty-based figure, implying that over half of the care population—around 50 million individuals all told—have fallen into the care gap.

These calculations are based on a dichotomy between those who do and do not need care. However, it seems reasonable to argue that even able-bodied adults need and deserve care in the form of health insurance. For healthy, productive adults, the inability to afford medical care when illness or injury strikes looms as a serious tear in the fabric of care. The 2004 Current Population Survey provides data on Americans with and without health insurance and suggests that our figures underestimate the care gap by over 25 million adults. Putting the numbers together, *around 75 million Americans, or over 26 percent of our entire population, are currently suffering from the care gap.*

If we take this broader view of the care gap, then the single policy shift that would shrink the gap most quickly is the provision of national health insurance.⁴ Arguably, however, over half of the population that needs care will continue to receive either none or substandard care until we also a) improve the quality of child and elder care, b) enhance the availability of after-school programs, c) markedly reduce poverty rates among children and the disabled, and d) reduce rates of disabilities. Reducing poverty rates and providing health insurance would each help to reduce rates of disability.⁵

We know how to close the care gap with policies related to the Work and Family Bill of Rights, by the Take Care Net. This Bill of Rights states in part that:

Working families have fundamental rights to financially sustain and to care for themselves and their families. These rights include:

⁴ Note, however, that national health insurance would also likely increase the number of elderly individuals with disabilities by promoting longevity.

⁵ On linkages between health care and disability prevention, see Phillips-Harris (1996). We also know there is some causation running from income to disability prevention (Atkins and Guisti 2004).

1. The right to annual paid family, medical and personal leave for full- and part-time employees. Minimum standards for leave are:
 - a. two weeks of employer-funded paid personal leave for all employees to be taken at the time of their choosing.
 - b. seven days of employer-funded sick time for personal or family illness
 - c. 12 weeks of paid leave for parents of newborn, adoptive and foster children, and for serious illness of the employee, a child, a parent or other relative, spouse or partner.
 - d. 16 hours of employer-funded leave to be taken in small increments for doctor's appointments, parent-teacher meetings, and other small necessities.
2. The right to negotiated flexibility over work hours and place:
 - a. the ability to shift between full-time and reduced hours as family and personal circumstances change.
 - b. equal pay rates and at least pro-rated benefits for reduced hours employees
 - c. no mandatory overtime.
 - d. flexible schedules and place of work, mutually agreed upon by employees and employers.
3. The right to quality, affordable child and elder care.
4. The right to a minimum wage set at a living wage level and indexed to inflation.
5. The right to adequate health insurance for all.

These rights shall apply to all regardless of gender, race, ethnicity, age, place of birth, religion, sexual orientation, or marital, family or disability status(www.takecarenet.org)

We can, and should, eliminate the care gap. Our children, and our children's children, would thank us for doing so.

Table 1: Those Needing Care

Age Group	Number needing care (1,000s)	Total number in group (1,000s)	Percent of group needing care
Up to 15 years	64,216	64,216	100%
16 to 64 years	21,495	185,871	11.6%
65 years and over	13,539	34,205	39.6%
Total	99,250	284,292	34.9%

Sources: 2004 American Community Survey, U.S. Census Bureau, *American FactFinder* <www.census.gov>, Table B18030, and CPS Annual Demographic Survey, U.S. Census Bureau, *American FactFinder*, Table POV01.

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