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OUR DEBT TO FAMILY CAREGIVERS

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Our society relies on families to provide care for disabled family members. They provide 80% of such care, and the financial value of their work is close to \$400 billion per year. If families did not provide this care, it would add 15 to 20% to the costs of health care in the United States.

There are people who believe that there is nothing remarkable about this. Aren't families supposed to take care of their own? It's basic morality, a fact of life in every human culture.

Perhaps, but it is also a fact about human cultures that families don't have to bear their burden alone. Extended family, neighbors, members of one's religions, philanthropic organizations, and other non-governmental social institutions often lend a hand.

What about government? In modern, non-communal, economically interdependent societies, government has to fill some of the gaps left by the shift from agrarian, communal societies to industrial and post-industrial societies. And of course, governments do step in. For example, in the U.S. Medicare and especially Medicaid pay for some help in the home, for day services, and for institutions such as nursing homes. In New York State the cost of long-term care in Medicaid alone is about \$12 billion. Nationally, it is about \$100 billion. The fact is that government does take on some of what would have been family responsibilities just a half-century ago—though it doesn't do much to support families who do not turn to government to take over caregiving.

So those who argue that it is right and natural for families to take care of their own without assistance are just mistaken about the facts of both human cultures generally and of contemporary Western societies. The question is not whether government *should* provide care for people with disabilities and support for their family caregivers, but *how and to what extent*.

This is a complex question because there are so many different forms of family caregiving.

- Parents care for young children and adolescents with disabilities.
- Parents also care for grown-up children with disabilities.
- Grandparents and other relatives take care of—indeed raise—grandchildren, nieces, nephews, siblings and cousins because their biological or their adoptive parents cannot.
- Working age adults take care of their parents, grandparents, or siblings.
- Married people and people in long-term committed relationships take care of their spouses and partners.
- Some young children are providing care for siblings, parents, and/or grandparents.

In addition to the differing relationships of family caregivers and their family members, there are different kinds of disabilities that they address. Some are transient; some are recurrent; some are permanent. Some are physical; some are mental. Many are co-occurring.

Each form of family caregiving has its own dynamics. Indeed, each case has its own dynamics. But there are some common dimensions of caregiving.

(1) Family caregiving is hard—very hard—and very stressful. It is hard to juggle the additional demands of a life to which caregiving has been added as a responsibility. The average family caregiver of an older adult, for example, spends about 20 hours per week providing care—the equivalent of an additional half-time job. It is hard economically; except for those who are so rich that expenses averaging \$5-6000 for older adults, and that can run to tens of thousands of dollars, per year are pocket change. And it is hard emotionally. That a family member is disabled is often a source of great sadness. How to take care of a person with disabilities is often a source of conflict within a family. Many family members experience guilt—about not doing enough for their disabled family members or about neglecting family members who are not disabled. The stress leaves caregivers at high risk of major depressive and anxiety disorders and of physical illness. Burnout is commonplace.

(2) It is also commonplace that—as Rodney Dangerfield would put it—family caregivers “get no respect.” Physicians and other treatment providers often will assume that family members (especially women) will be caregivers no matter what it takes. When they are smart and humane, physicians may assign someone, such as a social worker, to help the person assumed to be a caregiver to work out what has to be done. But most of the people we know who are or have been family caregivers report that not only do they get no help; it fell to them to help the medical professionals, who deal with these situations everyday, to think through what had to be done to manage.

Fundamental to the failure to provide support for family caregivers is the fact that very few medical professionals regard family caregivers as equal members of the treatment team. The pros figure everything out; we caregivers get our instructions.

(3) Most family caregivers find it difficult to get all the services their family members need or that they themselves need. There are three major reasons for this. First, there is a dreadful shortage of services, especially good services. Second, many, maybe most, people don’t know what services would be helpful or how to get access to them when they do exist. Third, people often need help at moments of crisis; and, with the exception of ambulances and emergency rooms, there are not many services that are available at the time of crisis.

While there are many more dimensions of the difficulties of family caregiving, these three alone have major implications for public policy, implications that are slowly being drawn and translated into helpful services and supports. Here are a few of them:

1. Government should fund family support. This should be a component of all governmental initiatives related to serving people with disabilities—home and community-based waiver programs, community physical and mental health centers, long-term care reform, etc. Respite is among the most requested forms of family support. Some family caregivers benefit from support groups, though many are just too busy to get to them. Other state-of-the-art approaches include family psycho-education, education about mental illness, training in problem-solving skills and in behavior management strategies, as well as highly individualized services that combine responsiveness to crisis, flexible delivery of individual counseling for caregivers, and family counseling designed to end recriminations and get family members on the same page.

In addition to services family caregivers often need economic support. Tax credit approaches are most frequently proposed.

2. Increased Access to Services: There need to be more community-based services for people with disabilities and for their family caregivers. And it is particularly important that these services be more accessible. That means that they have to be available at hours when family caregivers can be free, that they have to be available in home and community settings, that they need to be available in the languages of minority populations—who are in fact more likely to provide caregiving at home than is the general population. Also critical are well-publicized sources of information, individualized needs assessments, and assistance to help steer people to the right place at the right time and to be sure they get the services they need.
3. Recognition of the Importance of Mental Health: Although disabilities are often primarily physical, for many people the primary disability is rooted in a mental condition such as schizophrenia, dementia, profound affective disorders, and/or severe anxiety disorders. For them the availability of good treatment for their mental condition is clearly critical. In addition, as is too frequently forgotten, people with physical disabilities often experience emotional problems or co-occurring serious mental or substance use disorders as well as physical disabilities. Failure to identify and respond appropriately to their mental health and/or substance use disorders can exacerbate their physical disabilities and increases their risk of premature mortality.

In addition, as we have noted already, family caregivers are at high risk of mental and physical disorders. They burn out and, as a result, disabled family members are at higher risk of placement in institutions. Addressing the mental health needs of family caregivers benefits them, the family members they care for, and a society trying to hold down the use of institutions.

4. Dissemination of Best Practices: In our experience most people, when they think about it, understand how difficult caregiving is for the family members who take it on. But they rarely think about it, and service providers from physicians to nurses, from social workers to home health aides, from case managers to protective services workers and more, do not know much about how to provide support for family caregivers. Public policy should include a determination to spread understanding and build competence.

Public policy initiatives in the four areas noted above would go far to give the kind of support that family caregivers need and deserve. As we said at the beginning, our society relies heavily on family caregivers and owes them a debt of gratitude. Isn't it time we begin to pay that debt?

(Michael B. Friedman will retire as The Director of the Center for Policy, Advocacy, and Education of The Mental Health Association and as Chair of The Geriatric Mental Health Alliance of New York at the end of June 2010. Kimberly Williams will succeed Mr. Friedman as the Director of the Center effective July 1, 2010. She will also continue to serve as Director of the Alliance. The opinions in this essay are their own and do not necessarily reflect the opinions of MHA or the Alliance. They can be reached at mbfriedman@aol.com or kwilliams@mhaofnyc.org respectively.)