

Changing The Chronic Care System To Meet People's Needs

People with special medical and supportive care needs often have to navigate several disparate financing and delivery systems to obtain the services they need.

by Gerard Anderson and James R. Knickman

ABSTRACT: Persons who are likely to be the heaviest users of medical and supportive care services—those with chronic illnesses, disabilities, and functional limitations—are often forced to navigate a system that requires them to perform most of the coordination functions themselves and is generally not organized around their needs. In 1996 an estimated 128 million Americans had at least one of these three conditions, and 9.5 million had all three. This paper examines the current programs designed to assist these persons and suggests changes in eligibility rules, coverage policies, and educational programs to provide a system more oriented to people's chronic care needs.

146

**CHRONIC
CARE SYSTEM**

AN ESTIMATED 125 MILLION AMERICANS had one or more chronic illnesses, fifty million had a disability, and fifteen million had a functional limitation in 2000.¹ Unfortunately, the medical care system is not oriented around the needs of persons with chronic illnesses; many persons with disabilities have difficulties obtaining appropriate services; and the long-term supportive care system does not facilitate access to some of the services that people with functional limitations need. The challenges to obtaining appropriate care, however, are exacerbated when a person has two or all three of these problems. Such persons often have to navigate a system that requires them to coordinate several disparate financing and delivery systems themselves, making it more difficult to obtain the full range of appropriate services.

In this paper we first estimate the number of persons who have chronic illnesses, disabilities, and functional limitations and then examine the number who fall into one, two, or all three categories.

Jerry Anderson is a professor of health policy and management and international health at the Johns Hopkins Bloomberg School of Public Health in Baltimore and national program director for the Robert Wood Johnson Foundation's Partnership for Solutions: Better Lives for People with Chronic Conditions. Jim Knickman is the foundation's vice-president for research and evaluation, in Princeton, New Jersey.

We compare the utilization, costs, and outcomes of such persons and examine some of the problems they encounter attempting to coordinate one or more services. The paper focuses on two problems: (1) the need to better integrate eligibility and coverage standards across disparate programs; and (2) the need to change the professional culture of clinicians.

Chronic Illnesses

Over the past 100 years the medical care system has evolved to become oriented primarily toward the treatment of acute illnesses. But these developments lag behind demographic trends. Care for chronic illnesses has become the most common reason why Americans seek medical care.² By 2000 an estimated 125 million Americans had one or more chronic conditions and were responsible for 75 percent of health spending.³ By 2020 a projected 157 million Americans will have one or more such conditions, accounting for 80 percent of health spending.⁴

■ **Inadequate clinical information systems.** A lack of convergence between persons' needs and the system's orientation can lead to numerous problems. Most clinical information systems, for example, do not permit clinicians to know what other clinicians are doing for a patient. Our analysis of Medicare claims data suggests that the average Medicare beneficiary with one or more chronic conditions is seen by eight different physicians during a year; this indicates that the potential scope of the problem is quite large.⁵ The need for coordination of care and integrated information systems becomes especially important when a person has multiple chronic illnesses (for example, heart disease, asthma, and depression), each of which might require treatment by a different specialist. In these cases, each clinician may be unaware of the exact treatments being delivered by the others.

A national survey conducted in 2000 indicates some of the implications of inadequate communication among clinicians. Approximately twenty million Americans with chronic illnesses received contradictory information from different health care providers during the year, eighteen million received a contradictory diagnosis for the same chronic illness, and seventeen million reported going to the pharmacist only to be told of a potential drug/drug interaction.⁶ Better communication among clinicians could reduce these numbers.

■ **Preventable hospitalizations.** Ambulatory care-sensitive conditions are hospitalizations that might have been prevented with good ambulatory care.⁷ We compared the number of such conditions in Medicare beneficiaries with one chronic illness to those with five or more chronic illnesses. Our analysis of the 1999 Medi-

care 5 percent standard analytic file shows that only 0.8 percent of Medicare beneficiaries with one chronic illness were hospitalized with an ambulatory care-sensitive condition during the year. However, 12.8 percent of beneficiaries with five or more chronic illnesses were hospitalized with an ambulatory care-sensitive condition.

■ **Insurance coverage.** Health care benefits generally provide better coverage for acute episodes than for ongoing care. Medicare, for example, does not cover some services needed by beneficiaries with chronic illnesses, the most prominent being prescription drugs. In addition, definitions of *medical necessity*, used by insurers to decide if certain services will be reimbursed, frequently restrict reimbursement to situations in which the person is showing improvement. As a result, services designed to slow the progression of a chronic illness may not be covered. For example, physical therapy coverage may end if the person is not showing any improvement, even though the treatment objective is to slow the progression of disease or maintain the present level of mobility.

Cost-sharing provisions are another coverage issue that may disproportionately affect persons with chronic illnesses. Such persons are more likely to spend more out of pocket on coinsurance and copayments and because of their higher use of services that their insurance does not cover.⁸

■ **Provider payment.** Payment systems are oriented to acute episodes. Some systems do not pay providers for the time they spend coordinating care with other providers. Payment rates are typically greater when the physician is treating an acute episode than when he or she is providing ongoing care or counseling. Physicians and other health care providers may respond to these signals and emphasize episodic over ongoing care.⁹

■ **Coordination of care.** Most clinical education programs emphasize hospital-based, episodic specialty care. As a result, less attention may be given to comorbid conditions or the need to coordinate care with other clinicians. Studies have shown that physicians are less likely to give adequate attention to chronic conditions that are unrelated to the reason for the patient's visit.¹⁰ An estimated sixty million Americans had multiple chronic illnesses in 2000, and the number is projected to increase to eighty-one million by 2020.¹¹ Clinical education programs need to give greater attention to coordination of care for these persons.

Functional Limitations

Functional limitations are a second way of identifying persons with special medical and supportive care needs, although some may have both chronic illnesses and functional limitations. Generally, func-

“Under Medicaid, a poor person is likely to be eligible for a wider array of services than is a middle-income person.”

tional limitations are measured using activities of daily living (ADLs) and instrumental activities of daily living (IADLs), although other instruments have been used.¹² Approximately fifteen million Americans had a functional limitation in 1995.¹³

■ **Evolution of the long-term care system.** The financing and provision of supportive services evolved very differently from those of medical care. Unfortunately, the differences in organization and financing are never clear to most people until the need arises for long-term care.

Long-term care services, such as custodial nursing home and personal care, were considered “social” rather than “medical” services by the crafters of early health insurance plans, and this perspective was adopted by the designers of Medicare. Thus, long-term care developed in an environment where the Medicare program did not provide long-term care benefits, and, with the exception of Medicaid, the medical model, not the supportive care model, has been adopted by most other third-party payers.

■ **Insurance coverage.** Most health insurance plans do not pay for custodial long-term care services. Medicare, for example, pays for some long-term care when it is rehabilitative, such as care after a stroke or a hip replacement. This means that benefits are limited because services are covered only as long as the person is showing improvement. Most private insurers have similar provisions. Medicaid is the major public source of service funding for persons with functional limitations. Other public sources include state-only programs, Administration on Aging programs, and Title XX of the Social Security Act, all of which provide support mostly for home and community services.

While the coverage and protection offered by these policies has improved over the years, limitations still exist. Insurance coverage for supportive services is less extensive than that for medical care services. Generally, eligibility criteria for public coverage include both functional limitation and financial criteria. Insurance coverage can have a major influence on treatment options. A physician, for example, needs to consider one range of possible services for a middle-income elderly person who has supportive care needs but can consider a different range of services for a poor elderly person who is eligible for Medicaid. Ironically, because of better coverage for supportive services under Medicaid, a poor person is likely to be

eligible for a wider array of appropriate services than is a middle-income person.

■ **Supportive care system.** The actual delivery of formal, paid supportive services includes a panoply of systems that vary with a person's specific needs. Services vary from "meals on wheels" programs to highly skilled nursing home care. Often, supportive services are not organized in a way that a frail person or a family can understand the full range of available services, how the services can be obtained, the costs and available subsidies, and the pros and cons of each type of service. According to a national survey, the most common information source about supportive services remains family and friends.¹⁴

A combination of scarcity of funding, complex eligibility requirements, and preferences of families has meant that informal care continues to be the most common method of providing supportive services. Almost two-thirds of those with functional limitations who live in the community receive support exclusively from family, friends, and volunteers.¹⁵ Fewer than 10 percent rely exclusively on formal, paid long-term care providers. Recent estimates suggest that the economic value of informal caregiving far exceeds what is spent on formal long-term care services.¹⁶

■ **Other concerns.** First, most information systems do not allow the various supportive care providers to share data on their patients. In addition, a person's medical care provider often will have little if any contact with the long-term care provider, and rarely will the medical care provider offer advice to the long-term care provider about managing the person's care.

People beginning to need supportive services often go as long as possible before entering the long-term care system when their condition has reached a crisis point. A detailed study of how people enter the long-term care system in Springfield, Massachusetts, for example, documented the unmet long-term care needs that occur for persons who lacked coordination of care.¹⁷ Most people who started to receive supportive care services did so only after some acute exacerbation, many of which might have been avoided if the person could have found needed long-term care services earlier.

Coverage for long-term supportive services is likely to be restricted to persons who qualify for Medicaid. As a result, only persons with low incomes and no assets can receive extended long-term care services. Although there is growing private long-term care insurance, out-of-pocket spending remains the most common means of paying for long-term supportive services for those who do not qualify for Medicaid.

Disability

The distinction between functional limitations and disability can be blurry because the definition of a disability may refer to functional limitations or ADLs. Government and insurance programs use the terms *disability* and *functional limitations* differently, however, when determining eligibility requirements.

According to the Institute of Medicine, disability “is the expression of a physical or mental limitation in a social context—the gap between a person’s capabilities and the demands of the environment. People with such functional limitations are not inherently disabled...It is the interaction of their physical or mental limitations with social and environmental factors that determines whether they have a disability.”¹⁸ The Americans with Disabilities Act of 1990 defined *disability* as a “a physical or mental impairment that substantially limits one or more of the major life activities of such individual.”¹⁹ Almost fifty million Americans have a disability according to U.S. Department of Education estimates.²⁰

Government agencies have applied these definitions in multiple ways to identify persons who qualify for specific government programs. The Social Security Act, for example, requires the use of one of the most restrictive criteria to determine who qualifies for disability benefits, primarily because its definition of disability incorporates vocational criteria.²¹ Workers’ compensation law defines disability more broadly as “reduced capacity to perform the activities of daily living or work.” The Department of Education uses a two-part qualification criterion to administer the Individuals with Disabilities Education Act (IDEA).²² According to the IDEA criterion, the child must have one or more of a specified list of disabilities but also be evaluated by a team of educators to determine if special education and related services are required.²³

Navigating A Convoluted System

Persons who need access to multiple programs are most likely to find that each program has different eligibility criteria, has different sets of providers, and is not organizationally linked. Very simply, these persons will be on their own to coordinate most of the services they receive and will find baffling inconsistencies about which services are covered and which are not. Only the most aggressive will receive all of the services they are entitled to.

We used the Medical Expenditure Panel Survey (MEPS) to examine the number and characteristics of persons who have one or more chronic illnesses, functional limitations, or disabilities.²⁴ According to our analysis, 128.2 million noninstitutionalized Ameri-

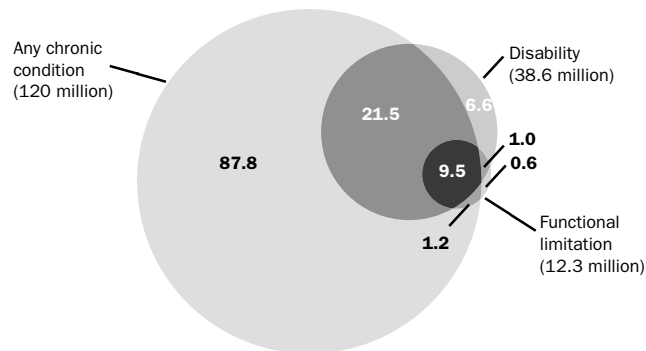
cans (48 percent of the population) had a chronic condition, functional limitation, or disability in 1996, and 9.5 million persons had all three (Exhibit 1).

■ **Implications of meeting multiple criteria.** The 141 million persons with no chronic conditions, functional limitations, or disabilities in 1996 had the lowest direct medical and indirect costs, had the least amount of health care use, and were most likely to be working or in school (Exhibit 2).²⁵ For the 87.8 million Americans with chronic conditions only, their costs and use of services was greater, and their school and work attendance was lower. For the 21.5 million Americans with one or more chronic conditions and a disability, the costs and utilization are nearly double, and the percentage going to work or school is nearly half the rate of those with a chronic condition only. The 9.5 million Americans with one or more chronic conditions, disabilities, or functional limitations have costs that are approximately sixteen times greater than those without any chronic conditions, disabilities, or functional limitations; are ten times more likely to be hospitalized; are twice as likely to use physician services and prescription drugs; and are one-sixth as likely to be in school or working.

152 CHRONIC CARE SYSTEM

■ **Characteristics of persons with more severe problems.** In 1996 an estimated 22.3 million noninstitutionalized Americans had three or more chronic conditions but did not have a severe disability or a functional limitation (Exhibit 3). There were 12.8 million noninstitutionalized Americans who had various combinations of severe disabilities, severe functional limitations, and/or three or more

EXHIBIT 1
Overlap Of Chronic Conditions, Disability, And Functional Limitation Among Noninstitutionalized Americans, 1996



SOURCE: Medical Expenditure Panel Survey, 1996.
NOTE: Amounts in millions.

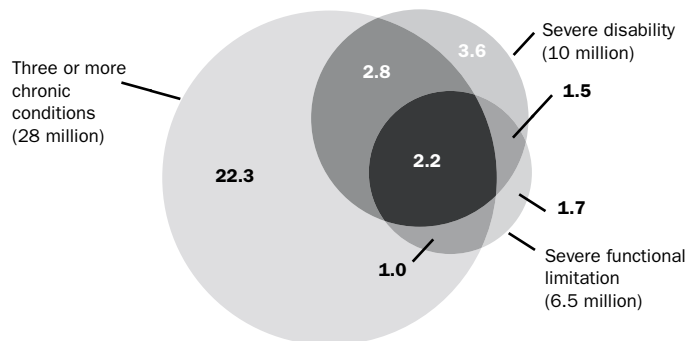
EXHIBIT 2
Implications Of Having A Chronic Condition, Disability, Or Functional Limitation, 1996

	Number of noninstitutionalized Americans (millions)	Total direct and indirect costs	Percent hospitalized	Mean number of physician visits	Mean number of home care visits	Mean number of prescription drugs	Percent 200% of poverty or below	Percent working or going to school
None of the three problems	141.0	\$ 1,102	3.4%	1.7	0.0	2.2	34.5%	81.2%
Chronic condition	87.8	4,107	7.6	4.6	0.3	11.0	27.4	74.7
Disability	6.6	2,519	8.4	3.3	0.5	3.8	47.6	54.7
Chronic condition and disability	21.5	8,512	17.0	8.3	2.1	23.5	41.7	39.7
Functional limitation	0.5	3,172	15.7	4.0	10.0	5.8	42.9	37.6
Chronic condition and functional limitation	1.2	8,917	34.4	7.9	10.9	22.2	60.7	35.0
Disability and functional limitation	1.0	20,202	20.0	6.4	12.3	10.1	65.1	26.1
All three	9.5	17,361	32.9	9.6	47.8	33.5	56.5	12.1

SOURCE: Medical Expenditure Panel Survey, 1996.

chronic conditions. These persons had the highest costs, had the most use of services, and were least likely to be working or going to school (Exhibit 4). In 1996, 2.2 million noninstitutionalized Americans had all three problems. A total of 35.2 million (12 percent of the noninstitutionalized population) had three or more chronic condi-

EXHIBIT 3
Overlap Of Three Or More Chronic Conditions, Severe Disability, And Severe Functional Limitations Among Noninstitutionalized Americans, 1996



SOURCE: Medical Expenditure Panel Survey, 1996.

NOTES: Severe disability is defined as being completely unable to work at a job, do housework, or go to school. Severe functional limitation is defined as needing help or supervision with any activity of daily living. Amounts in millions.

EXHIBIT 4
Implications Of Having Three Or More Chronic Conditions, Severe Disability, And/Or Severe Functional Limitation, 1996

	Number of noninstitutionalized Americans (millions)	Total direct and indirect costs	Percent hospitalized	Mean number of physician visits	Mean number of home care visits	Mean number of prescription drugs	Percent 200% of poverty or below	Percent working or going to school
3+ chronic conditions	22.3	\$ 7,195	17.3%	9.4	3.4	28.3	31.7%	47.9%
Severe disability	3.6	16,362	22.2	7.6	11.2	19.7	62.8	22.2
3+ chronic conditions and severe disability	2.8	20,859	37.0	13.4	9.3	45.3	58.2	6.7
Severe functional limitation	1.7	9,571	25.1	5.9	27.3	11.6	56.4	26.7
3+ chronic conditions and severe functional limitation	1.0	17,524	43.9	12.1	59.7	34.3	62.2	20.6
Severe disability and severe functional limitation	1.5	25,231	26.2	6.0	65.6	21.6	62.3	8.5
All 3	2.2	24,358	47.8	11.0	78.1	46.8	51.3	3.0

SOURCE: Medical Expenditure Panel Survey, 1996.

NOTE: See Exhibit 3 for definitions of severe disability and severe functional limitation.

tions, a severe disability, or a severe functional limitation.

When we disaggregated the MEPS data by three age groups (5–17, 18–64, and 65+), most of the trends shown in Exhibits 2 and 4 remained valid (data not shown). Most of the differences were anticipated: For example, a much lower percentage of people over age sixty-five were working or in school. The analysis by age did show one surprising difference: Children with disabilities and functional limitations appeared to have greater difficulty carrying out their daily activities than adults (ages 18–64) did, perhaps because disabled children are likely to have developmental difficulties, particularly mental retardation, that inhibits normal school progress.

Delivery System Challenges

A challenge to policymakers in the coming decades will be to make it easier for persons with special medical and supportive needs to receive appropriate care. A wide range of experts have suggested that persons with special medical and supportive care needs would benefit if medical, disability, and supportive services were better coordinated. Walter Leutz, for example, makes the case that integration should improve efficiency, user satisfaction, and actual outcomes.²⁶ How this integration could be accomplished is the subject

of great debate. The following section focuses on two factors: (1) eligibility and coverage standards, and (2) professional culture.

■ **Different eligibility and coverage standards.** Different eligibility standards can make it difficult for a person with multiple special medical and supportive care needs to receive appropriate care. Most supportive services are means-tested, most medical services are not, and most disability income programs are dependent on the person's ability to return to work or school.

Return-to-work incentive. In the United States, a key driver in the design of disability programs is the concern that cash payments will erode work incentives. The primary objective of most disability income-support programs is to have people return to work as soon as possible. Workers' compensation experts have expressed concern that the duration of medical services or rehabilitation services may be limited to accomplish this.²⁷ The push to return people to work can also impede access to medical services because of the eligibility link between income support and medical services. For example, the loss of Medicaid benefits typically is associated with a determination that the person no longer qualifies for Supplemental Security Income (SSI) benefits. As a result, there is concern that health insurance may not be available once the person has returned to work. Programs such as Ticket to Work and new Medicaid payment options are recent attempts to rectify this problem.

Funding "games." A second problem is that funding for different services often comes from different programs. Unfortunately, most programs have a financial incentive to shift expenditures from their program to other programs. For example, the parents of a child who qualifies for both Medicaid and special education could find themselves negotiating with both programs, each of which wants the other program to pay a larger share of the cost. These funding "games" are also played across different levels of government. For example, states may encourage providers to substitute services that are covered by Medicare for services covered by Medicaid even when the person could do equally as well with a lower-cost service that is covered by Medicaid.²⁸

Different payment systems. A third problem is that different third-party payers use different payment systems to reimburse providers. Workers' compensation programs, for example, typically pay much more than Medicaid programs do. As a result, providers may have different financial incentives to treat patients in different ways depending on the funding source.

Perhaps less well known is that individual third-party payers also use different payment systems for different types of providers. This can make coordination of care across providers difficult. The March

“Most payment systems do not explicitly reimburse any provider for coordination of care.”

2001 Medicare Payment Advisory Commission (MedPAC) report, for example, lists eleven different payment systems used by Medicare to pay its providers.²⁹ This report identifies three problems that could affect Medicare beneficiaries if the payment systems are not aligned and rates not set appropriately. First, if some payments are set too high and others set too low, then “providers have incentives to shift the mix of services they produce towards relatively profitable services and away from unprofitable ones.” Second, when rates are set too high or too low, providers have incentives to furnish too many units, “exposing patients to unnecessary health risks,” or too few units, causing providers to “limit patients’ access to care or stint on the services.” Third, in the absence of risk adjusters for managed care plans, “providers have incentives to engage in risk selection, seeking only the least costly patients and avoiding those who are expected to need unusually expensive care.”

Coordination of care. Another problem is that most payment systems do not explicitly reimburse any provider for coordination of care. Instead, the coordination function is included in the evaluation and management fee that clinicians may receive as part of a visit. This fee is not dependent on the number of chronic conditions a person has or the number of clinicians involved. As a result, some clinicians may be unwilling to undertake the considerable effort to coordinate care across multiple clinicians and institutions.

Managed care plans could improve coordination of care. However, staff and group models—which were organized to emphasize coordination of care—have not emerged as the dominant organizational approach. The fastest-growing forms of managed care, independent practice associations (IPAs) and preferred provider organizations, have not focused on coordination of care.

One approach that could improve coordination across different programs is to give individuals greater autonomy over their spending. For example, the Cash and Counseling Demonstration and Evaluation operated by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services is an attempt to integrate income support and service benefits. Cash and counseling programs are intended to educate Medicaid beneficiaries about the range of available services and thereby give them greater choice and freedom in obtaining the assistive services they need. This includes purchasing services such as transportation or hiring family members

or friends as caregivers. Although cash payments are designed to cover services, they can be used to support family members as caregivers, thus indirectly providing additional family income. Participants can carry over their cash benefits in special accounts, which enables them to save for a time when extra services may be required.³⁰

■ **Professional culture.** Most services and treatment protocols are now organized to take care of medical “episodes,” not ongoing care. The typical physician generally thinks in terms of his or her “day’s appointments.” Most of these appointments are triggered because a patient with a chronic condition has an immediate medical problem. The strength of this approach is that it is strongly oriented toward problem solving, at which most physicians are adept. This is how medical school and residency programs train physicians, and payment systems reinforce it. Unfortunately, the model does not work well for persons with chronic conditions, because the focus is on “appointments” and not on people. This focus often means that the same physician may not see that person when the next problem occurs. Ten percent of persons with chronic conditions report that they do not have a usual source of care.³¹

More training is needed in ambulatory care settings, where ongoing care of chronic conditions, functional limitations, and disabilities can be emphasized. Medical school curricula and residency training are being slowly revised to respond to the growing number of persons with chronic conditions. The American Academy of Pediatrics (AAP), for example, recently published a comprehensive review of pediatrics education that calls for major changes in pediatric education.³² The AAP recognizes that “although pediatricians in past decades spent much of their time dealing with acute illnesses, the care of patients with chronic conditions is now beginning to dominate many pediatric practices.” Similar efforts are occurring in other medical specialties and among medical school deans.

Achieving Coordination And Integration

The medical, supportive care, and disability systems need to provide better services to persons with chronic conditions, functional limitations, and disabilities. First, it is important for coordination to occur within each sector. The more difficult challenge, however, will be to integrate programs across the three. One approach is to create integrated financing and delivery programs. For example, the social health maintenance organization (S/HMO) and Program of All-Inclusive Care for the Elderly (PACE) models integrate acute care and some coverage for long-term care into one delivery system. A number of states are experimenting with integration approaches for frail populations who are eligible for both Medicare and Medicaid.

Other programs give persons more autonomy and encourage self-determination. This may be appropriate for some people as long as they and their providers have the requisite information. Cash and Counseling, Ticket to Work, and linkages between SSI and Medicaid are other examples.

If coordination within and across the programs is so important, why is it not happening more regularly? One explanation is that individual programs have their own constituencies. Long-term care, medical care, and disability income-support programs have different orientations and supporters. Providers develop around these programs and form a second constituency for the status quo.

The problems of care coordination are subtle, and often the issue does not capture the attention of the public until they personally face complex coordination problems. Also, while many people see the problems caused by poor coordination, they generally do not have enough knowledge to frame possible solutions. Without a demand “push” for improvements by the public, changes will occur slowly.

POLICYMAKERS NEED TO TAKE THE LEAD in crafting solutions. Because so many of those with special medical and supportive care needs are covered by government programs, government policymakers can help to identify specific solutions. Breaking down government “silos” that inhibit integration across multiple programs is one approach. It is also critical for actual providers of care and the leaders of health care delivery organizations to devise creative organizational solutions to meet the care needs of this population. For the system to change substantially, the public, policymakers, and providers will all need to recognize the number of people having difficulties with the current system and initiate solutions.

.....
This work was supported by the Robert Wood Johnson Foundation as part of the project Partnership for Solutions: Better Lives for People with Chronic Conditions.

NOTES

1. How each of these numbers was derived is explained later in the paper.
2. In this paper a chronic condition is one that has lasted or is expected to last twelve months or longer and either requires ongoing medical care or places limitations on at least one of the following: age-appropriate task performance, basic self-care, independent living skills, or social interactions.
3. S. Wu and A. Green, *Projection of Chronic Illness Prevalence and Cost Inflation* (Santa Monica, Calif.: RAND Health, October 2000).
4. Ibid.
5. We analyzed Medicare claims data (standard analytic 5 percent file) for 1999. *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes were classified into acute or chronic conditions based on

the ambulatory care group (ACG) classification system. For aged Medicare beneficiaries who were classified as having a chronic condition, we counted the number of visits to different physicians during the year. Some visits may not have been related to the chronic condition, but this cannot be ascertained from the claims data.

6. Harris Interactive conducted a nationally representative telephone survey of 1,669 Americans from March to November 2000 (54 percent response rate) to determine if they had a chronic condition. They were given the same definition of a chronic condition as in Note 2. Those with a chronic condition were asked a series of questions about their interaction with the health care system. Based upon the number of people who responded that they had a chronic condition and the percentage who said they had a problem with the health care system, we estimated the number of Americans with a particular problem with the health care system. Harris Interactive, *Survey on Chronic Illness and Caregiving* (New York: Harris Interactive, January 2001).
7. J. Caminal, "Hospitalization Due to Ambulatory Care Sensitive Conditions: A Performance Indicator of Primary Health Services" (Doctoral thesis, Bellaterra [Cerdanyola], Autonomous University of Barcelona, 1999).
8. W. Hwang et al., "Out-of-Pocket Medical Spending for Care of Chronic Conditions," *Health Affairs* (Nov/Dec 2001): 267–278.
9. Medicare Payment Advisory Commission, *Report to Congress: Medicare Payment Policy* (Washington: MedPAC, March 2001).
10. See, for example, D.A. Redelmeier, S.H. Tan, and G.L. Booth, "The Treatment of Unrelated Disorders in Patients with Chronic Medical Diseases," *New England Journal of Medicine* 338, no. 21 (1998): 1516–1520.
11. Wu and Green, *Projection of Chronic Illness Prevalence and Cost Inflation*.
12. A. Bayer and C. Synan, "Functional Assessment Scales," in *Principles and Practice of Geriatric Medicine*, 3d ed., ed. M.S.J. Pathy (Chichester, N.Y.: John Wiley and Sons, 1998).
13. J. McNeil, *Americans with Disabilities*, Current Population Reports P70-61 (Washington: U.S. Census Bureau, August 1997).
14. Harris Interactive, *Survey on Chronic Illness and Caregiving*.
15. U.S. Department of Health and Human Services, *Informal Caregiving: Compassion in Action* (Washington: DHHS, June 1998).
16. The national economic value of informal caregiving was estimated to be \$196 billion in 1997. In comparison, national spending on formal home health care was \$32 billion, and national spending on nursing home care was \$83 billion. P.S. Arno, C. Levine, and M.M. Memmott, "The Economic Value of Informal Caregiving," *Health Affairs* (Mar/Apr 1999): 182–188.
17. S.M. Allen and V. Mor, "Unmet Need in the Community: The Springfield Study," in *To Improve Health and Health Care 1997: The Robert Wood Johnson Foundation Anthology* (San Francisco: Jossey-Bass, 1997), 132–160.
18. A. Pope and A. Tarlov, *Disability in America: Toward a National Agenda for Prevention* (Washington: National Academy Press, 1991).
19. *Americans with Disabilities Act*, P.L. 101-336, 26 July 1990, 104 Stat. 327.
20. National Institute on Disability and Rehabilitation Research, "Correction for Final Long-Range Plan for Fiscal Years 1999–2003," *Federal Register* (7 December 1999), 68575–68614, <www.ed.gov/legislation/FedRegister/other/1999-4/120799d.html> (19 September 2001).
21. 20 CFR, Chapter III—Social Security Administration (1 April 1999).
22. *Education for All Handicapped Children's Act of 1975*, P.L. 94-142.
23. B. Knoblauch and B. Sorensen, *IDEA's Definition of Disabilities*, ERIC Digest E560, Pub. no. ED429396 (Reston, Va.: ERIC Clearinghouse on Disabilities and Gifted Education, April 1998).

24. MEPS is a national random survey of 22,061 Americans. How chronic conditions were identified is discussed in Note 2. Functional limitations were defined as the need for help or supervision with any ADLs or IADLs. Disability was defined by either (1) the use of assistive technology; (2) difficulty walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or toppling, or standing for long periods of time; (3) any limitation in work, housework, or school; (4) social/recreational limitations; (5) cognitive limitations such as confusion or memory loss, problems making decisions, or requiring supervision for their own safety; (6) vision problems, such as blindness, inability to read newsprint or recognize familiar people; (7) deafness or difficulty hearing; (8) age-related limitations for children; or (9) presence of a physical or mental health problem that limited school attendance or required a special school program for children.
25. Indirect medical cost was calculated using a human capital approach—for example, work hours lost multiplied by the wage rate for that person.
26. W.N. Leutz, “Five Laws for Integrating Medical and Social Services: Lessons from the United States and the United Kingdom,” *Milbank Quarterly* 77, no. 1 (1999): 77–110, iv–v; J. Alper and R. Gibson, “Integrating Acute and Long-Term Care for the Elderly,” in *To Improve Health and Health Care 2001: The Robert Wood Johnson Foundation Anthology*, ed. S.L. Isaacs and J.R. Knickman (San Francisco: Jossey-Bass, 2001), 101–117; and B. Davies “The Reform of Community and Long-Term Care of Elderly Persons: An International Perspective,” in *International Perspectives on Community Care for Older People*, ed. T. Scharf and C.C. Wenger (Brookfield, Vt.: Ashgate, 1995), 21–38.
27. A.E. Dembe and J.S. Himmelstein, “The Workers’ Compensation Health Initiative: At the Convergence of Work and Health,” in *To Improve Health and Health Care 2001*, ed. Isaacs and Knickman, 119–143.
28. G. Kenney, S. Rajan, and S. Soscia, “State Spending for Medicare and Medicaid Home Care Programs,” *Health Affairs* (Jan/Feb 1998): 201–212.
29. MedPAC, *Report to Congress: Medicare Payment Policy*, Table I-2.
30. P.J. Doty, “The Cash and Counseling Demonstration: An Experiment in Consumer-Directed Personal Assistance Services,” *American Rehabilitation* (Summer–Autumn 1998): 27–30.
31. Harris Interactive, *Survey on Chronic Illness and Caregiving*.
32. “The Future of Pediatric Education II: Organizing Pediatric Education to Meet the Needs of Infants, Children, Adolescents and Young Adults in the Twenty-first Century,” *Pediatrics, The Future of Pediatric Education II* (Supplement, January 2000): 163–212.