

# The "Re-Invention" of Personal Assistance Services<sup>1</sup>

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No doubt the origin of personal assistance services (PAS) dates to prehistoric times, the first time a cave man got injured and his hunting buddy helped him hobble home. There his mate took over tending the wounds, nurturing him back to health and full participation in the various activities of the daily life of the clan.<sup>2</sup> If, perchance, the injury was life-threatening, our fellow was totally out of luck. And the same if it involved recuperation over a period of time, in the absence of long-term care.

Morris, Caro, and Hansan (1998) pretty much pick up the trail from there in their survey of the historical context of home and community-based long term care.<sup>3</sup> Their story begins with the total reliance on family and individual charity in early Western civilization, continues through the local public authority embodied in the poorhouses established by the late 16th century Elizabethan Poor Law, and brings us up to the present social welfare system. Throughout history home care has been defined as a medical need and provided in a social welfare context.<sup>4</sup> Ironically, 20th century Medicaid long-term care was a program originally designed to meet the health care needs of the poor, but it has become a middle-class entitlement. Medicaid now provides publicly funded nursing home care (or home and community-based care) once individuals have divested themselves of assets and "spent down" to indigent status.

The combination of the aging trend in the general population, which actually began with the Industrial Revolution, recent medical advances that allow greater numbers of younger persons to survive devastating injury or illness with severe disabilities, and the family fracturing effects of modern day geographic mobility have conspired to expand the need for home care and to make its provision more problematic. In the early 20th century scientific advances in knowledge of disease, new therapeutic interventions, increasing medical specialization, and the evolution of the hospital as primary health care institution contributed to the redefinition of health care throughout the industrialized world in the late twentieth century.<sup>5</sup> But it was the economics of the health care industry itself that ultimately led to the development of in-home personal assistance services. And this happened long before the recent health care trends toward managed care and cost containment efforts in the newborn conservative political climate.

Gini Laurie traced "The Origins of Attendant Care Programs in the U.S." to a deinstitutionalization effort for polio survivors at Rancho Los Amigos Hospital in Los Angeles, California, in 1953 (World Rehab. Fund, 1985, p. 4). The lifelong care needs of respiratory polio survivors were accommodated by an innovative home care program projected to cost less than one third the cost of hospitalization for a group of 152 survivors who returned to live with their families. Initially attendants were trained at the hospital, but as high turnover became a problem, it was realized to be more efficient (and less costly) to train the polio survivors to train their own attendants. "The average hospital time [for respirator users] was cut from one year to 7 months. It was found that home care cost one tenth to one fourth less than hospital care." (Ibid., p. 5)

The National Foundation for Infantile Paralysis (March of Dimes) had established specialized regional centers in 1950 to save money by concentrating services to polio survivors. Although funding for these centers had to be abandoned less than ten years later (1959), persons served through them used them and their empowering experience as models for the nationally funded, geographically dispersed Independent Living Centers that evolved from the Independent Living Movement. Ed Roberts, often acclaimed as the father of the Berkeley Center for Independent Living, first in the nation, was an alumnus of the Rancho Los Amigos regional polio respiratory center who became a national leader of the Independent Living Movement. Attendant care or PAS has always been high on the agenda of this movement.

As early as 1960, partly in response to the June 1959 cessation of home care funding by the National Foundation for Infantile Paralysis, there were efforts to effect national attendant care legislation. Although these efforts were ultimately unsuccessful, and to this date there is no national PAS program, polio survivors like Ed Roberts and concerned, forward-thinking health care professionals like his mentor Dr. Leon Lewis were successful in sponsoring statewide attendant care legislation in California (Ibid.)

The concept of home care and human interdependence in family life for elderly persons was as old as human civilization. But the idea of younger persons with severe disabilities and chronic health care needs receiving paid in-home assistance to prevent institutionalization seemed at first a novel one. In-home attendant care, later termed "personal care assistance," had evolved as a non-medical solution to a problem that had initially been conceived as a medical need, but one that had proven too costly to be served within the health care system to which 20th century Americans increasingly turned for help with the age-old matters of illness, disability, and death.

The issue of who was to pay for personal assistance services when personal assets were exhausted became a pressing one. Private health insurance, primarily designed to spread the risk of catastrophic costs of acute illness, universally declined to cover these services using a moral hazard argument and the specter of large cumulative costs. They argued that, since in-home assistance with routine tasks from personal hygiene to housekeeping and food preparation was something everyone could use and would prefer to have, hordes of persons might clamor to be considered qualified for PAS despite the social stigma still attached to disability. And most persons with severe disabilities who would qualify for PAS had a lifetime need for the services which translated in most cases to very high cumulative lifetime costs. PAS home care remains a public sector issue.

Nosek aptly stated: "The real issues are how much community care society is willing to pay for, who should receive it, and how it can be delivered effectively." (Nosek, 1991, p. 5) Most experts agree that the amount of paid PAS provided as of this writing (April 2001) is but a fraction of that required. It is asserted that there is great unmet (because unfunded) demand for paid PAS. Hundreds of thousands, perhaps millions of Americans with disabilities fall into one of the following categories: persons unnecessarily institutionalized because they do not have family support to live independently; persons living substandard lives in the community in squalid, unhealthy, isolated, and dangerous home situations due to inadequate family or other supports; persons living marginally tolerable existences in their homes who are forced to rely on grudgingly provided unpaid in-home services from relatives and friends who resent the drain on their own work and family lives; persons whose (under)paid caregivers are

unreliable, tardy, prone to absenteeism, indolent, slipshod in task performance, unfeeling, rude, even abusive. On the other side of the coin are many PAS providers (family, friends, neighbors, workers) who are either unpaid or distinctly underpaid, but do their best to meet wide-ranging needs for assistance in a caring, humane fashion, to the very best of their own limits and abilities.

In recognition of the great need, there have been, over the last few decades, efforts to create an entitlement to PAS at a national level. To date they have been unsuccessful, although awareness of the need has been heightened. In 1989 Congressman Claude Pepper introduced a bill (U.S. HR 2263) that would have provided comprehensive long-term in-home care insurance coverage for all persons with disabilities assessed to be dependent in at least two activities of daily living. The bill was never voted on by the Congress (Binstock, 1992). A national PAS entitlement for persons needing assistance with at least three of five basic activities of daily living was a feature of the early Clinton Administration's proposed Health Security Act. The effort was ill-fated (Kennedy, 1997).<sup>6</sup>

The emphasis in federal proposals on a need for assistance with multiple basic activities of daily living, Kennedy points out, frames policy debate of the issue in sheer physical survival terms and is thus exceedingly harsh (Kennedy, 1997). On the judicial front in 1995 the U.S. Supreme Court let stand a Third Circuit Court of Appeals favoring the plaintiff (the Helen L/Idell S. decision) in a suit demanding in-home attendant care services based on ADA (Americans with Disabilities Act of 1990) rights to community integration, those rights having been violated by the Commonwealth of Pennsylvania's providing her services in a nursing home, a living situation the Court found to be "unnecessarily segregated."

In June 1997 then Speaker of the House Newt Gingrich introduced the Medicaid Community Attendant Services Act (MiCASA) as H.R. 2020. The bill, which had considerable bipartisan support, nevertheless died a quiet death. A revised and expanded update entitled the Medicaid Community Attendant Services and Supports Act (MiCASSA) was filed in the 106th Congress by Senators Tom Harkin and Arlan Specter in November of 1999. The bill had been reworked and refined with more inclusion of additional constituencies and their concerns - the aging, persons with mental retardation, and persons with chronic mental illness. The addition of "supports" in the title specifically referenced the cognitive supports to independent living that are needed by many persons who are more independent in physical self care activities.<sup>7</sup>

But it has been the fear of overwhelming unmet need that seems to have stalled action to date in the Congress. The dimensions of the need have a very wide range<sup>8</sup> depending on the definition of eligibility for PAS which is usually set by the number of the five activities of daily living (ADLs)<sup>9</sup> with which consumers need help. Estimates also vary according to whether one includes persons with limitations in performing ADLs, those who actually require another person's assistance with those ADLs, or those who need standby assistance or supervision. Further inclusion of needs for assistance with instrumental activities of daily living (IADLs) broadens the population parameters by including many persons with cognitive and sensory impairments, who may be virtually independent in basic self care.

Another key variable in estimating the costs of a national PAS entitlement program, and hence its feasibility, is the service delivery model utilized. Researchers at

the World Institute on Disability (WID) examined the costs of six models, including the Independent Provider (IP) model with and without medical supervision, the Agency Provider (AP) model with and without medical supervision, the High Management model, and the Legislated Reimbursement Rate model in which states have decided to pay home care agencies and individual providers at equal rates (Egley, 1996). Egley's overall findings is that: "Anticipating double the current usage, services can be provided to people with any ADL or IADL *limitation* [emphasis as in original] under the different service models for the following [national] annual costs: Individual Provider without Medical Supervision \$12.8 billion, State Legislated Rates for Reimbursement \$12.9 billion, Agency Provider without Medical Supervision \$22.2 billion (for Medical Supervision add 10% to [either of] the above), High Management Provider \$54.3 billion, Consumer Choice of AP and IP \$14.0 billion." (Egley, 1996, pp. 129-130)

In fact, the disability advocacy community had already "demedicalized" the issue by not insisting on home health agency provided home care services for a diverse set of reasons: 1) The cost of service provision by trained health care personnel was quickly realized to be prohibitive. 2) Most survivors of crippling illness or trauma had had their fill of experience with the medical model of service delivery in the hospitals and nursing homes from which they sought liberation. 3) Inadequacies of personal resources (functional capacity, funds), family resources (money and time), and the environmental barriers (both architectural and attitudinal) were driving their need for paid PAS providers.<sup>10</sup> 4) The ethos of the Independent Living Movement was independence and self direction to the maximum degree possible.

Researchers at WID had formulated a comprehensive definition that has pretty well stood the test of time and become the basis of the proposed federal legislation to create a national PAS program: "These [PAS] tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation[,] laundering and long term heavy cleaning and repairs; 4) infant and child related tasks such as bathing, diapering and feeding; 5) cognitive or life management activities such as money management, planning and decision making; 6) security-related services such as interpreting for people with hearing or speech difficulties and reading for people with visual disabilities" (Ibid., fn. 1 to p. 1).

Because PAS is crucial to the ability of most persons with severe disabilities to live independently in their communities, there has been, as noted above, political action in the United States on behalf of a national PAS program in order to permit state-to-state equity of access to publicly-funded attendant care. Maximization of consumer control is a key feature of most of the policy declarations on the topic. The President's Committee on Employment of People with Disabilities conducted a 1993 teleconference project the report of which is entitled *Operation People First: Toward a National Disability Policy*. About 17% of persons with disabilities participating in the teleconference characterized PAS as "the single most significant issue facing people with disabilities" (PCEPD, 1994, p. 11). The two specific recommendations supported the ADAPT<sup>11</sup> proposal of "...shifting 25% of federal Medicaid funds that currently are spent on nursing homes to personal assistance and in-home care programs...[and that]...personal assistance services must be community based and consumer driven..." (Ibid., p. 12).

The National Health Council focussed on personal assistance services as one of eight crucial issues in its 1994 report on *A Health Care Reform Summit: Building Bridges to Find Solutions, A Chronic Illness and Disability Response to Health Care Reform*: "[PAS] can mean the difference for people with disabilities or chronic conditions between institutionalization and living and caring for oneself in the community....Personal assistance services and home-based care can be delivered at a lower cost and with better social outcomes." (National Health Council, 1994, p. 8)

The National Council on Independent Living called for a reversal of the primacy of institutionalization in long-term care provision, with supported in-home care to become the primary and preferred option (NCIL, 1994). From a civil rights perspective, the Consortium for Citizens with Disabilities, in presenting a full slate of specific PAS policy recommendations, stated its position thus: "CCD and other disability organizations view the passage of comprehensive federal personal assistance services legislation as essential to realizing the full promise of the Americans with Disabilities Act (ADA)." (CCD, 1992, p. 1)

More recently the Long-Term Care Working Group of the National Summit on Disability Policy (Dallas, TX; April 1996), of which the author was a participant and contributor, featured PAS in its policy recommendations, published by the National Council on Disability as *Achieving Independence: The Challenge for the 21st Century, A Decade of Progress in Disability Policy Setting the Agenda for the Future* (NCD, 1996). Citing figures from the American Association of Retired Persons published in 1994, the report notes that total U.S. spending for all forms of home health care in 1991 were one tenth that spent on nursing home care (almost \$60 billion) and that public sources (federal, state, and local governments) accounted for over 72% of home care funding.<sup>12</sup> Looked at another way, some 82% of federal expenditures for long-term care go to funding nursing home care, six times that the federal government spends on home and community-based services (NCIL, 1994).

The NCD report voiced concern over the elimination or curtailment of federal Medicaid entitlement implicit in then-current calls for devolution of Medicaid policy responsibility to the states: "Current proposals to eliminate the federal entitlement to Medicaid threaten the major source of funding for community-based long-term services for approximately two million recipients with disabilities....Without Medicaid's support for long-term community-based services [including PAS], people with disabilities would be at risk for institutionalization." (NCD, 1996, pp. 98-99) This report made a sweeping definition of long-term services that people with disabilities need in order to live independently: "Long-term services include personal assistance services to assist people with activities of daily living, readers for individuals who are blind, interpreter services for people who are deaf, habilitation, rehabilitation, assistive technology and supported employment services" (Ibid. p. 96). Note that reader and interpreter services are separate items, not included in PAS as in the WID definition above.

Suggestions for financing the expansion of personal assistance services in the U.S. included: adopt the ADAPT proposal, noted above, that 25% of Medicaid nursing home expenditures be diverted to community PAS; reallocate Medicaid funds for ICF-MR (intermediate care facility for persons with mental retardation) institutions to community PAS; institute a federal requirement that states include PAS as a benefit in the basic Medicaid plan they offer; make Medicaid waivers for attendant care, now subject to

five-year renewals, permanent; modify Medicare benefits to include PAS and cover persons under 65;<sup>13</sup> create a Title XXI of the Social Security Act for funding PAS; create an annually indexed PAS block grant; create an individualized economic support program with economic parity (net of disability-related expenses) for persons with disabilities (Litvak, 1992). As noted above, current PAS funding is primarily through Medicaid and only available to persons who are Medicaid-eligible. Provisions in the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999 encourage states to implement Medicaid "buy-in" programs that will allow working persons with disabilities to purchase the broad Medicaid coverage, which includes in-home PAS attendant care and costly medications like the newer psychotropics, by paying premiums based on family size and monthly income.

The author has several years of experience as a PAS consumer with this type of program<sup>14</sup> and previously as a privately funded employer of independent providers that he has routinely paid hourly wages considerably in excess of state's reimbursement amount<sup>15</sup> in order to entice providers to make the daily trips to his suburban home. Typical independent providers he has employed were recent immigrants, sometimes without green cards, whose knowledge of English and work history and skills were insufficient for competitive private sector employment. Others were American citizens with disabilities themselves (substance abuse, mental illness, chronic disease). The character of the independent provider/PAS consumer relationship could, in many such cases, be characterized as mutual exploitation. Both parties to the relationship agree to less than desirable terms because both are at a disadvantage. The independent provider cannot find other employment and values (and often insists upon) cash "under the table" while the PAS consumer, consciously or unconsciously, trades more control for lesser quality services and possibly fewer than his/her authorized service hours in order to pay more per hour.

There are ways in which the Independent Living Movement's preference for consumer-directed, independent provider PAS could be considered making a virtue of a necessity. Some of the tradeoffs, from the PAS consumer's viewpoint, could be represented as: more control for lower skill level, lesser quality assurance for greater distance from the health care professions, lower hourly wages paid (with quality of service implications) for more hours of service, greater immediate security for lesser long-term security (high provider turnover), more direct management for lesser worker accountability, assumption of personal injury liability (for self) in exchange for denial of personal injury liability for the provider, and the classic 'something is better than nothing.' For many prospective independent providers this last dictum probably also prevails. Some work, be it part-time with low pay, irregular hours, no benefits, no future, and not highly socially valued or respected, beats no work at all.

In addition to different service provider models there are different PAS management and funding models that may be applied in the provision of consumer-directed PAS and they have different program implications and sometimes different constituencies. The income subsidy model, of which the voucher model is a variant, is one in which the PAS consumer receives a cash allotment to fund his/her services and may spend it in any way he/she likes, including non-service uses that may take priority. This is the closest to what classical economics might consider the optimally efficient model. The Veteran's Administration funds such a program as do six states that

supplement SSI (Supplemental Security Income) checks for persons needing attendant services. (Litvak, No date) Consumer cooperative models, pooling funds and functioning similarly to home health agencies, but operated by and for consumer members, are more common in Europe. However, New York City's Concepts of Independence is a large example of this type in the U.S. (Ibid.) Litvak used the Pennsylvania Attendant Care Program as the prototype for what she called the "management choice model" in which the PAS consumer delegates as much responsibility as desired to the program contractor provider agency for the county in which he/she resides.

The "cash and counseling" model is the latest variant on the cash subsidy model described above. It might be described as the "enlightened economically efficient" model as it pairs cash allowances for PAS "with counseling services (information, advice, and training) to help consumers make choices and manage their money." (Cameron, 1995, p. 23) A four-year national initiative, one year for enrollment and three years of operations, to test out cash and counseling was jointly sponsored by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the U.S. Department of Health and Human Services (DHHS). Although the study is now concluded its full findings have not yet been published.

#### Endnotes

1. This article draws, often verbatim, on the literature review contained in Chapter 2 of the author's recent Brandeis University doctoral dissertation (Glazier, 1999).

2. Social theorist Talcott Parson opined, "Health is vital, because the capacity of the human individual to achieve is ultimately the most crucial social resource. Illness is, to the sociologist, essentially a disturbance of this capacity to perform in socially valued tasks and roles." (Parsons, 1960, p. 281)

3. The following text, summarizing that book's history of home care, draws from the author's recent Disability Studies Quarterly book review of same.

4. This irony makes Medicaid-funded PAS almost an oxymoron, by definition a non-medical service for which the only funding, other than private pay, is public health insurance. See Glazier, 1996.

5. See Starr, 1982, for a thorough treatment of the transformation of health care in America.

6. "The Long-Term Care (LTC) section of President Clinton's Health Security Act [Senate Bill 1757 in the 103rd Congress] included a provision for home and community-based care. This provision requires that: The State plan included, in the array of services made available to each category of individual with disabilities, both agency-administered and consumer-directed personal assistance services (Sec. 2104(1)(c))." (Flanagan, 1994, p. 4)

7. Other major differences between the original MiCASA and MiCASSA include: 1) Consumer choice of service delivery mode is mandated rather than only referencing home health agency delivery with a consumer-directed independent provider option. 2) "Consumer-directed" is carefully defined in the bill itself. 3) There are now two major

thrusts to the legislation, expansion of services and effecting of system change. 4) The states are to be bound by a "maintenance of effort" requirement that prevents cutbacks in other service areas. (For the text of both the MiCASA and MiCASSA bills and answers to frequently asked questions about the legislation see: <http://www.adapt.org/casa>.)

8. See Burke (No date) as an example of the debate about unmet need and the costs of a national PAS entitlement, the original MiCASA bill in this case.

9. ADLs are basic self care activities like eating, bathing, dressing, while IADLs are less immediately critical activities like shopping, money management, cleaning.

10. "Research has shown that functional capacity [loss] accounts for only about half of the reason why persons need personal care assistance. [Insufficiency of] Family resources, environmental barriers, and [un]availability of technological aids account for the rest." (World Rehab. Fund, 1985, p. 12)

11. American Disabled for Attendant Programs Today, a disability advocacy organization.

12. Proportions given in this text are derived from summary data presented in the report noted previously (NCD, 1996, p. 97).

13. Currently Medicare provides certified home health agency services (not PAS), but only to persons who can prove they are home-bound, unable to leave their homes for anything other than medical appointments. Thus non-aged disabled Medicare beneficiaries receiving home care services cannot leave their homes on more than an occasional basis even for family reasons and certainly not for work. HCFA's interpretation of "confined to the home" is being challenged by a class-action lawsuit by the Center for Health Care Law (Dittbrenner, 1998).

14. Massachusetts' leading edge CommonHealth (Medicaid buy-in) program for working persons with disabilities and parents of children with exceptional medical needs.

15. Recently CommonHealth, in recognition of the tight labor market, increased PCA (personal care assistant) wages to \$10.12 per hour. The program, which once required consumers to fund their monthly PCA expenditures out of pocket and then be retrospectively reimbursed, currently operates on a fiscal agent model. PCAs are legally the employees of disabled consumers, each of which has a Federal Employer ID Number; they are paid by checks bearing the consumer's name, processed by the payroll service vendor of the fiscal agent, and mailed to the consumer for distribution.

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