



# Health Snapshot

## An Introduction to Spinal Cord Injury

### Personal Assistant Services



#### What Are Personal Assistant Services?

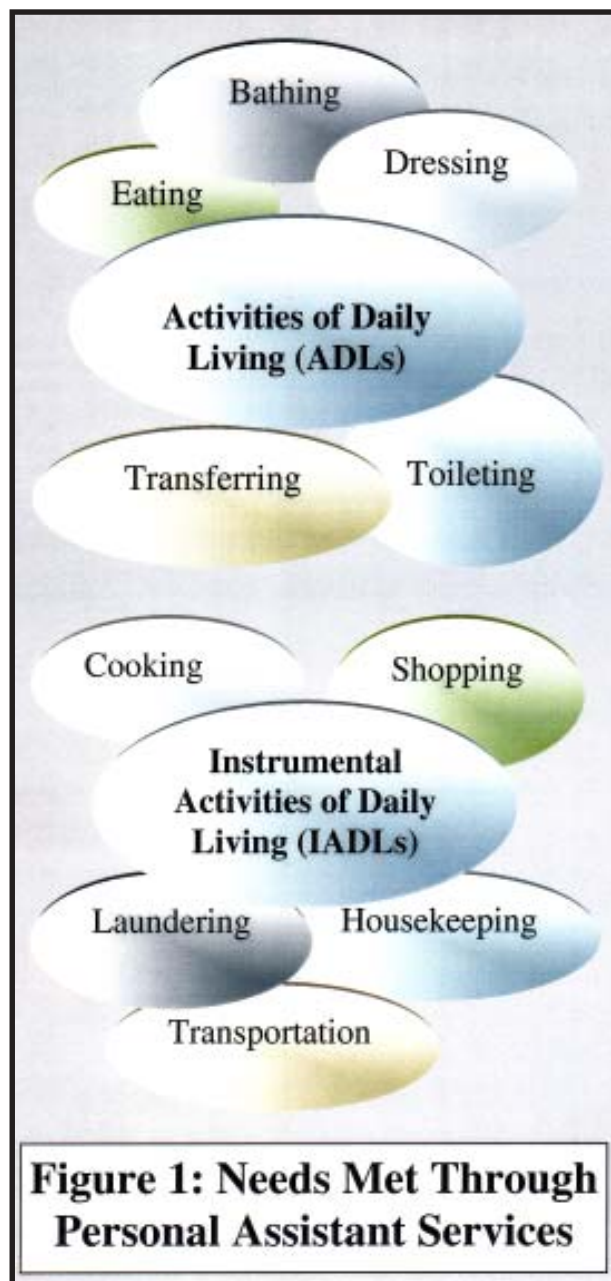
Many individuals with spinal cord injury (SCI)\* and other disabilities require assistance in the performance of various tasks necessary to survival and daily functioning. Such tasks are often divided into two sub-groups that serve to distinguish primary or life-sustaining needs from secondary or household-maintaining needs. Needs that must be provided to ensure survival are often classified as ADLs or *Activities of Daily Living*. Other needs, related to household maintenance, are classified as IADLs or *Instrumental Activities of Daily Living* (Figure 1).

An individual with a severe disability may require help with some ADLs and IADLs and not require assistance with others. Moreover, the scope and extent of an individual's need often changes over time. Since with SCI the degree of sensation and mobility varies, persons with SCI can manifest diverse conditions of disability that often require a variety of different levels of assistance. The primary purpose of *Personal Assistant Services* is to coordinate and accommodate such changing, multiple combinations of assistive need.

Assistance can be administered in a community-based setting or an institutional setting. Assistance can be provided via assistive technology (e.g., wheelchairs), through environmental and/or structural adaptation, through human beings (personal assistants or personal care attendants) or trained animals.

#### Who Provides Personal Assistant Services?

The *Independent Living Movement*,\*\* which arose out of the struggle for civil rights in the 1950s



**Figure 1: Needs Met Through Personal Assistant Services**

and 1960s, became a major force in the ongoing realization of equal rights for persons with disabilities. With the rise of the Independent Living Movement, the term personal assistant services has widely

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\* For more information about spinal cord injury, view the Health Snapshot "A Brief Overview of Spinal Cord Injury" available at this Internet web link: <http://www.muhealth.org/~momscis/snaps1.htm>

\*\* For more information about the Independent Living Movement, view the article "Independent Living: From Social Movement to Analytic Paradigm" at this Internet web site: [http://www.impactcil.org/phil\\_history/dejong.htm](http://www.impactcil.org/phil_history/dejong.htm)

become synonymous with community-based long-term care that is usually provided through human assistance and financed mainly through public funds. Formal assistance is now financed across the nation through state Medicaid programs and federal Social Security Title XX block grants designed to support social services at the state level.

## Agency Model

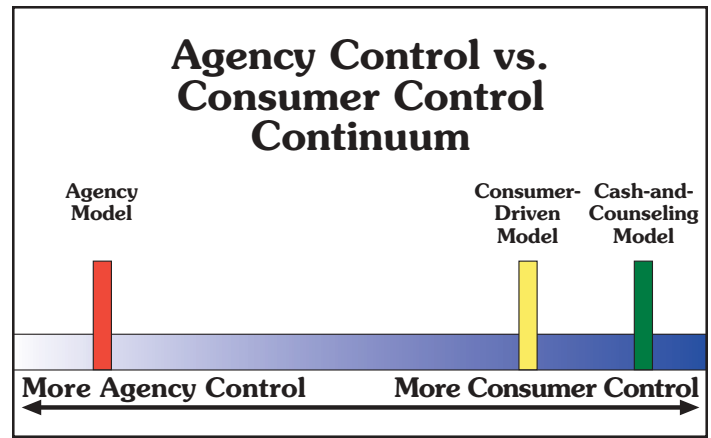
Until the rise of the Independent Living Movement and the push for community-based assistant services, public-funded assistance was delivered almost entirely through an *agency model*, which relies heavily on nursing homes and home health agencies. Historically, agency-driven assistive services were viewed as an extension of acute/rehabilitative care, rather than as long-term social supportive services. Personal assistants were generally hired, managed, and paid by long-term care institutions.

## Consumer-Driven Model

In contrast to the agency model, the *consumer-driven model* is less institutionally based and allows persons with disabilities a greater degree of control over their services. *Centers for Independent Living* often assist and educate persons with disabilities (often referred to as *consumers*) in how to maintain adequate assistance. In contrast to the agency model, under the consumer-driven model the consumer is primarily responsible for management of the personal assistant, including interviewing, task assignment, hiring, and firing. Generally, personal assistants are paid through a fiscal intermediary agency.

## Cash-and-Counseling Model

Recently, a third alternative vehicle for delivery of personal assistant services has arisen in the form of the *cash-and-counseling model*. This model could be viewed as an offshoot of the consumer-driven model in that the individual with SCI has an even greater degree of control. This new model greatly



reduces the administrative third-party component. Under cash-and-counseling, consumers' individual needs are evaluated (often by Centers for Independent Living or local aging offices) and payment is provided directly from the government entity (usually Medicaid) to the person with the disabling condition. That individual, provided with access to accounting, legal, and educational resources, is then empowered to budget the payment and to manage their own personal assistant services with less restriction and less dependence on a third-party player.

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The Health Snapshot "Agency vs. Consumer-Directed PAS", compares the differences between an agency directed and a consumer-directed personal assistance program in Missouri. It is available at: <http://www.muhealth.org/~momscis/snaps1.htm>

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